PSYCHO-SOCIAL PROBLEMS IDENTIFIED BY ADULT BONE MARROW TRANSPLANT SURVIVORS.

BY: ADRIENNE RIES

Dissertation submitted to the Faculty of Social Science and Humanities in partial fulfilment of the requirements for the degree of Master of Social Science in Clinical Social Work at the University of Cape Town.

April 1996

ABSTRACT

Bone marrow transplantation (BMT) offers many patients who are diagnosed with leukaemia, lymphoma, myeloma and aplastic anaemia the opportunity of increased survival. Chemotherapy is one of the most common forms of treatment for cancer patients en-route to BMT, which is often a concomitant stressor in the patient's life. Due to the side effects of chemotherapy, patients are often required to remain in a protective isolation unit for several weeks at a time. In most cases, BMT constitutes the final phase of the treatment process. This procedure is not without it's risks and may create significant psychosocial stress for patients.

Social work intervention in the Department of Haematology at Groote Schuur Hospital has focused primarily on newly diagnosed patients and those patients undergoing transplantation. However, with the increased success of BMT, it is important to address the needs of cancer survivors.

An ongoing support group with BMT survivors, provided the opportunity for the researcher to conduct a qualitative exploratory study of how survivors conceptualise and describe their current lives. To this end, fifteen group sessions were tape recorded and the self-identified issues raised by the members were organised into themes.

It was ascertained that adjustment post BMT was stressful for most of the survivors. In general, survivors experienced numerous losses in terms of intimate and social relationships, memory and sexual functioning. Anxiety was pervasive and was heightened by an underlying fear of relapse. However, survivors also acknowledged the positive benefits of having been diagnosed with cancer and undergoing a BMT, such as improved family relationships, renewed interest in religion and the changing of attitudes and values.

Members utilised numerous coping skills including denial, avoidance, rationalisation, confrontation and problem solving in an attempt to master their situation.

The group experience was viewed favourably by members who formed a strong bond as a result of their shared experiences. Some of the survivors were able to use the group to express fears that they felt uncomfortable to express elsewhere.

BMT survivors enter a distinct phase of adjustment with the re-entry into their pre-morbid lifestyles. Preparation is essential if this phase is to mastered. Further research across race and cultural groupings is required in order to ensure that social work intervention is appropriate to all in South Africa.

Amazing, isn't it, how some people see the basket half empty and others see it half full. Some see life hopeless; others hopeful. Even when things are less than perfect, if you can think of the good, the beautiful, the hopeful, you'll be more than sustained - you'll conquer.

-anonymous

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I, Adrienne Ries would like to thank the following people who made this study possible:

My supervisor, Shona Sturgeon, for her expert guidance and keen interest in this study. I would also like to thank her for her time which often went beyond the call of duty.

I am indebted to Michael de Villiers, the Assistant Director of Social Work Services at Groote Schuur Hospital who encouraged me to register for my Masters Degree.

Many of my colleagues in Social Work Services have made sacrifices in order to support my endeavours and for this I am very grateful. I would particularly like to thank my colleagues, Andre de Vos and Lungi Hlakudi for working in the Department of Haematology during my absence.

I pay tribute to Professor Nicholas Novitzky, the Head of the Department of Haematology at Groote Schuur Hospital, for his vision and his belief in the psychosocial support of his patients.

I would like to thank the entire staff of the Haematology Department for their support and encouragement.

Kathy Martin and Amiem Boltman were always available and willing to assist me with the organisational aspects of this study. I appreciate their assistance.

A special word of thanks to Hans Soltau who co-facilitated the groups with me. His thought provoking insights, his expert group facilitation and his ability in containing my anxiety is greatly appreciated.

I thank Jessica Gerretsen for readily assisting me in collating archival material despite her own hectic work schedule.

I am most grateful to Seanette Wilson who so generously and willingly assisted me with the tables and the printing of rough drafts .

I owe an enormrous gratitude to Bashier Koopman for assisting me with the editing and printing of the final document.

I thank Richard Charlewood for his unfailing assistance through numerous computer crises.

I appreciate the friendship and support given to me by Ruksana Patel. Her ability to encourage and sustain me to remain focused and goal directed, was no mean feat.

I am eternally grateful to Yunus Seth and my family for their support, encouragement and their unfailing belief in me.

I particularly valued the cheerful attitude and willing assistance given to me by the staff of CANSA's Cancer Information Service. I thank them for the opportunity of allowing the group to meet in such pleasant facilities.

Without the group, this study would not have been possible. I have personally gained and learnt tremendously from the members. I pay tribute to their courage and perseverance and thank them for allowing me into their world, to share some of their pain and to rejoice in their victory.

LIST OF ABBREVIATIONS

BMT	Bone Marrow Transplantations
GVHD	Graft versus Host disease
RT	Radiotherapy
TBI	Total Body Irradiation

CHAPTER ONE

INTRODUCTION TO THE STUDY

This chapter provides a background to the study, followed by a brief overview of the statement of the problem, the aims of the study, and the research design. The chapter will conclude with a brief description of the methods of data collection and analysis and the limitations of the study.

1.1 BACKGROUND AND CONTEXT OF THE STUDY

Life threatening haematological disorders and other malignancies were first described in the 19 century, and have historically been associated with a sense of hopelessness and a fatal outcome.(Lesko 1990a). During the last 20 years, there have been enormous strides in the treatment of certain cancers originating and\or affecting the bone marrow (the body's factory for producing blood cells). A relatively new medical procedure, a bone marrow transplant (BMT), provides hope for many patients diagnosed with certain cancers such as leukaemia and lymphoma, as well as other bone marrow disorders such as severe aplastic anaemia, that were once thought incurable.

The traditional medical method of treating the `haematological cancers', that is cancer of the bone marrow, is with chemotherapy. This is essentially a cocktail of `anti-cancer' drugs given orally or intravenously. Depending on the type of disease, different protocols of treatment are used. The desired effect is to achieve a state of remission where the disease is no longer evident, in other words, the bone marrow has been purged of cancer cells. The remission state is consolidated by further courses of chemotherapy. There are numerous side effects from the chemotherapy. These include amongst others, nausea, diarrhoea, hair loss and infertility

(Novitzky, N. pers.comm. 1996).

In the process of killing off the cancer cells, the chemotherapy also damages healthy cells which usually regenerate. Due to high dose chemotherapy, the immune system is temporarily impaired. Consequently, it is important to take special precautions to defend against infections. For this reason, patients are admitted to a protective isolation unit for a month or more, until their immune system is capable of fighting off infections again.

Unfortunately, it is often the case that chemotherapy provides only a temporary solution. For this reason, if it is medically indicated, patients are offered a bone marrow transplant (BMT) which is considered to be the most aggressive form of therapy available (Novitzky, N. pers.comm. 1996). The likelihood of a cure is increased, however, this cannot be guaranteed. In the event of a relapse post transplant, no further treatment option exists.

This procedure is highly specialised and requires an expert medical team who are experienced in BMT. Groote Schuur Hospital is one of only three centres in South Africa that perform BMT's. Thus, this necessitates that patients from upcountry, who require treatment, are uprooted from their homes and families for the duration of the treatment and recovery period which can last as long as 18 months. Those patients who are in remission and who are undergoing a BMT, are given high doses of chemotherapy and radiotherapy which permanently destroys their marrow. They are then `rescued' with the donor\`cleaned' marrow which is infused intravenously.

Bone marrow transplant survivors have therefore experienced, and continue to experience, numerous difficult situations to which they need to adapt. When first diagnosed, the news of a potentially life-threatening illness is devastating for patients and their families, whose lives, hopes and dreams are disrupted. Patients

often find the experience overwhelming and confusing as they have to contend with unfamiliar medical terms, new routines and numerous invasive medical tests and procedures. Anxiety may be heightened as they attempt to adapt to new circumstances over which they have little control. It is likely that patients require counselling to help them work through the many possible issues of loss including that of health, body image, reproductive functioning, role function and occupational functioning etc. It appears that the hope for a cure is one of the factors that sustain patients and their families through the difficult period of extensive treatment and recovery, both of which are physically and psychologically demanding.

1.2 STATEMENT OF THE PROBLEM

When the researcher started working in the Haematology Department of Groote Schuur Hospital twelve years ago, the social worker's role was not well recognised. Patients were referred mainly for concrete services. Gradually the social worker's role was expanded to include the counselling of patients who were diagnosed with life threatening illnesses. The main focus of intervention at that time, was crisis work and `death and dying' counselling.

More recently, the team has adopted a biopsychosocial model of intervention as proposed by Engel (cited in Rowland 1990a:25). This model allows for the patient's intrapsychic, interpersonal, familial, cultural, societal as well as biological circumstances and needs to be taken into account. With the increased success rate of bone marrow transplantation, patients are offered a realistic hope of disease-free survival. The focus of social work intervention has remained crisis orientated. However, there has been a hopeful shift to counselling patients on coping with surviving cancer. Yet, there has been little focus on the survivors' needs once they are discharged.

Awareness of this problem prompted the researcher to undertake a needs assessment of the patients in the department, who indicated their interest in becoming involved in a support group. In facilitating this support group, psychosocial difficulties facing BMT survivors, such as anxiety and social isolation became evident. It was felt that more rigorous investigation and documentation of these needs could lead to an improved service delivery which may lead to improved quality of life for survivors.

Furthermore, according to Forester et al. (1993) there has been increasing emphasis on the need to demonstrate the cost-effectiveness of psychiatric and psychological intervention in medical settings. This is particularly relevant in South Africa, where resources are limited and there is an increasing need to focus on primary health care. Enormous steps must therefore be undertaken, to enable patients to benefit from the highly specialised programme and to ensure that those who benefit from bone marrow transplantation are physically, socially, psychologically and economically productive.

1.3 AIM OF THE STUDY

The aim of this study was to gain a better understanding of the biopsychosocial problems experienced by BMT survivors, and to determine their coping mechanisms. A further aim was to discover whether BMT survivors considered a group experience to be helpful in the process of dealing with these issues.

1.4 OUTLINE OF THE STUDY

The research design is exploratory and qualitative in nature. A non-probability sample of BMT survivors from the Haematology Department of Groote Schuur Hospital were invited to join an ongoing support group. The contents of 15 sessions were tape recorded and analysed in terms of the self-identified issues raised by the members. The limitations of the study were the lack of generalisability due to the

research design, the small sample used and the lack of representation across population groups. A further limitation was that the majority of the members were from middle class backgrounds, thereby reducing perspectives across social class. Due to the possible weaknesses in terms of validity, a co-facilitator was used to monitor the group process and data analysis.

Chapter two will examine the medical processes that impact on BMT survivors from their initial diagnosis until the BMT. In chapter three the psycho-social implications of these processes will be outlined. In order to understand the psycho-social problems of BMT survivors, it is necessary to understand the medical conditions, as well as the treatment processes leading up to, during and post BMT. The medical conditions and treatments will therefore be briefly described

CHAPTER TWO

MEDICAL CONTEXT

All patients, (with the exception of severe aplastic anaemia patients), who are ultimately offered bone marrow transplantations (BMT) will have undergone procedures such as chemotherapy and irradiation, which in themselves are stressful. In order to understand the psycho-social problems of BMT survivors, it is necessary to understand the medical conditions, as well as the treatment process leading up to, during post BMT. The medical conditions and treatments will therefore be briefly described.

2.1 MEDICAL CONDITIONS

Table 1 describes some of the types of cancers that are able to be treated by meansof a bone marrow transplant.

Table 1 TYPES OF CANCERS

LEUKAEMIA	This is a cancer of the blood forming cells. It occurs when immature or mature cells multiplyinan uncontrolled manner in the bone marrow. There are four main types of leukaemia. Two acute, more aggressive types and two slow growing, chronic types
LYMPHOMA	This is a general term for the cancers that develop in the lymph system. they are difficult to categorise. Some remain dormant for years, while others are extremely aggressive.
MYELOMA	This begins in the plasma cells and other white blood cells that are part of the immune system. It weakens and damages bone, destroying the normal bone tissue. It is a slow growing cancer.

Source: Adapted from Morra, M. & Potts, E . Choices 1994

2.1.1 The Leukaemias

Leukaemia is a cancer of the bone marrow. Bone marrow is a spongy tissue found inside bones. In the adult, this organ is located mainly within the breast bone, skull, hips, ribs and spine. It contains the stem cells that produce the body's blood cells. These blood cells include white blood cells (leukocytes), which fight infection; red blood cells (erythrocytes), which carry oxygen to and remove waste products from organs and tissues; and platelets, which enable the blood to clot (NYSERNet 1992).

In leukaemia, the stem cells in the bone marrow malfunction and there is an unrestrained proliferation of a "clone" of immature white blood cells. These abnormal white blood cells develop a growth advantage and gradually "crowd out" the normal blood cells leading to anaemia, which may increase the risk of infection and bleeding.

The four main types of leukaemias -`cancer of the white blood cells'- are classified according to the type of blood cell line affected and may pursue an acute or chronic course. Diagnosis is confirmed by means of a bone marrow biopsy.

2.1.2 Lymphoma

Lymphoma is a general term for the group of malignant disorders involving predominantly the lymph nodes. It was first described by Hodgkin in 1832 and are usually separated into Hodgkin's lymphoma and non-Hodgkin's lymphomas. Both groups are classified into stages, which is important in determining the extent of the disease and treatment. The diagnoses of lymphoma is made from a lymph node biopsy, splenic tissue or a bone marrow sample (Lesko 1990a).

2.1.3 Myeloma

Myeloma, a slow growing cancer, involves one of the white blood cells called

plasma cells. The myeloma cells have the ability to spread beyond the bone marrow into the bone itself. As a result, it causes bone pain and weakened bones. Since more than one area of the bone may be affected, the disease is often called multiple myeloma. It is difficult to diagnose in the early stages and is often diagnosed on it's sequelae, for example: anaemia, high protein levels in the blood, hypercalcaemia or renal failure (Stein, M. pers.comm. 1996).

2.1.4 Severe aplastic anaemia

Severe aplastic anaemia is not a form of cancer. It is characterised by bone marrow failure which is an inability to produce adequate blood cells. The diagnosis is confirmed by means of a bone marrow biopsy (Stein, M. pers.comm. 1996).

2.2 TREATMENTS

2.2.1 Chemotherapy

Chemo means `chemical' and *therapy* means `treatment' thus, chemotherapy is simply the treatment of cancer using chemical drugs. The chemicals destroy the cancer cells, either by interfering with their growth or by preventing them from reproducing. Chemotherapy usually involves a variety of drugs (Mora & Potts 1994).

Traditionally, leukaemia, lymphoma and many other cancers have been treated with chemotherapy, (a combination of `anti-cancer' medication), and/or radiotherapy (a form of X-ray treatment). Both chemotherapy and radiotherapy have been historically perceived as more frightening to patients than surgery (Holland & Lesko 1990).

Depending on the diagnosis, the majority of bone marrow transplantation patients are admitted on several occasions, for approximately a months duration, to a protective isolation unit. Here, they receive scheduled chemotherapy, (this is

usually administered with plenty of fluids over several days) which is required to ablate the abnormal cells in the bone marrow. The initial course is to induce a state of disease remission, (a state where the disease is not evident), which is a prerequisite for BMT. Subsequent courses of chemotherapy `consolidate' the remission (Novitzky, N. pers.comm. 1996).

In the majority of patients, the chemotherapy is administered through an indwelling siliconised catheter, which is a central venous line inserted under general anaesthetic. All blood samples are drawn from this line and all blood products and medication are administered through this line, as is intravenous or parentral nutrition, if required. One of the advantages of this catheter, is that it greatly reduces the morbidity associated with having to endure repeated venipunctures (Lesko 1990b). However, Malcolm et al. (cited in Lesko 1990b:166) found that insertion of this line can cause profound anxiety, depression, fear and negative body image. An associated risk of the catheter one of infection (Novitzky, N. pers.comm. 1996).

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2.2.1.2 Side effects

These therapies not only kill the abnormal cells but destroy normal cells found in the bone marrow as well. The side effects are numerous and depend on the type of chemotherapy administered, as well as the individual's reaction to the drugs. Examples of these side effects include nausea, vomiting, diarrhoea, constipation, skin discolouration, hair loss, temporary changes of the sense of taste or smell, infertility and impaired immunity which increases the susceptibility to infections. Heart problems and thyroid gland malfunction can also result from some forms of chemotherapy (Morra & Potts 1994).

Severe nausea and vomiting can lead to loss of appetite, weight loss and lack of nutrition, but it can be minimised by the effective use of anti-emetics (anti-nausea drugs). Relaxation and visualisation techniques are also often helpful in reducing this side effect (Morra & Potts 1994). Partial or complete hair loss, which may include body hair, is usually temporary and regrowth occurs after treatment has stopped.

Combination chemotherapy (when more than one drug is being used in the treatment) in particular, can damage or destroy the cells in testes and ovaries from which sperm and eggs evolve. Radiation causes similar problems, and can damage the uterine lining and\or fallopian tubes. Infertility caused by chemotherapy and\or radiation may be either temporary or permanent. It may occur both at low doses as well as the higher doses which is administered pre-BMT. For women who have not yet begun, or who wish to expand their family, it is usually disturbing to hear that their chances of falling pregnant post BMT, will most likely be reduced. Men suffer a similar consequence of chemotherapy\radiotherapy, which may also be very distressing for them (NYSERNet 1992).

Not all patients undergoing a BMT, experience infertility. The likelihood varies according to the patient's age, gender, sexual maturity, the type and amount of chemotherapy and\or radiation administered, and the preventive steps taken during treatment. Thus, many patients with leukaemia or Hodgkin's disease are often infertile before a BMT as a result of prior chemotherapy. Before commencing treatment, sperm-banking is an option offered to men (NYSERNet 1992). At present, cryogenic preservation (freezing) of embryos is unavailable at Groote Schuur Hospital.

Women frequently experience cessation of menstruation during chemotherapy, with premature menopausal symptoms caused by the abrupt reduction in normal hormonal levels. All patients who agree to treatment with chemotherapy should be advised of and counselled in terms of possible changes in libido, sexual functioning and fertility (Holland & Lesko 1990).

2.2.2 Radiotherapy

Radiotherapy is the use of high energy rays to destroy cancer cells. (Jackson 1994) Patients may receive total body irradiation (TBI) as part of the preparation for BMT. Patients attend planning sessions a few days before the treatment commences. Patients have to lie very still while the treatment is being given. However, radiotherapy is not painful. The patients attend several sessions of radiotherapy over a number of days, during which time they are alone in the room. The radiographers who are in an adjoining room are able to watch the patients by means of a television monitor. Conversation between the radiographer and the patients can take place during the procedure and this often helps to reassure patients (Jackson 1994).

2.2.2.1 Side effects

Significant side effects of the radiotherapy such as anorexia, nausea, vomiting,

fatigue, weakness, sore throat and diarrhoea often appear within two to three weeks. Changes in exposed skin may become irritating for patients. Immunosuppression also occurs with radiation which reduces the likelihood of the donor marrow being rejected. The most psychologically distressing delayed effects of irradiation is usually sterility. It is essential that all of the side effects are discussed with the patient particularly, the risk of sterility. Counselling the patient and his\her significant other, is an important part of the process of acceptance (Holland 1990a).

2.3 PROTECTIVE ISOLATION UNIT

Prior to the Department of Haematology's transfer to the New Groote Schuur Hospital in 1988, the BMT programme was in it's infancy with mortality and morbidity rates being high. Subsequent to the transfer to the Protective Isolation Unit, these rates improved significantly (Novitzky, N. pers.comm. 1996).

Patients are at risk of acquiring unusual infections which are potentially lethal. As a precaution, they are required to remain in a protective isolation unit until their immune system is capable of mounting a defence against infections (Novitzky, N. pers.comm. 1996). The protective isolation unit consists of 10 single en-suite bedrooms, five of which are laminar-airflow rooms, which have special air filtering equipment. In the main, patients are required to remain in these rooms for the duration of their admission. The rooms are equipped for intensive care and each have a telephone for incoming calls, a television, a refrigerator and an exercise bicycle.

With the exception of those with severe aplastic anaemia, most of the patients undergoing a BMT, will have spent prolonged periods in the protective isolation

unit, prior to the actual transplant.

Precautions are taken to limit the patient's exposure to harmful bacteria, viruses and fungi during this period. Reverse barrier nursing is therefore practiced (Novitzky, N. pers.comm. 1996). This requires that the staff and visitors change into special clothing and aprons, and wash their hands when in contact with the patient and his\her environment. Fresh fruits and flowers and vegetables are not allowed as these may harbour potentially harmful bacteria. Visiting times are liberal with a maximum of six visitors allowed per day for each patient.

Although the protective isolation environment reduces the risk and severity of infection in patients, it also imposes prolonged physical and psychological isolation from family and loved ones. Patients are encouraged to bring in personal belongings to brighten up their rooms and introduce familiarity. Psychological regression due to stress and illness can be minimised by encouraging patients to participate in their own care and to remain as self-sufficient as possible. Furthermore, problems that do occur are often transient and readily manageable (Lesko 1990c). The year in which the BMT was performed at the Groote Schuur Hospital is likely to affect the adjustment to some extent. It would appear that the success of the programme has impacted positively on the psychological morbidity of the patients due to an increasing population of survivors.

2.4 TYPES OF BONE MARROW TRANSPLANTS

The types of transplants offered at Groote Schuur Hospital are described in Table II.

Table II TYPES OF TRANSPLANTS

TYPE	DESCRIPTION
PERIPHERAL STEM CELL SUPPORT WITH AUTOLOGOUS BMT	Peripheral stem cells are taken from the patient's own blood in a process similar to donating blood. The patient's own bone marrow is harvested, frozen and later re-infused, together with the stem cells, through the indwelling catheter. This occurs after high doses of chemotherapy and radiotherapy, known as "conditioning" are used to destroy
ALLOGENIC BMT	Bone marrow is donated by a matched brother or sister. After conditioning, the marrow is infused into the patient through the indwelling catheter

Source: Unpublished observation: Adrienne Ries.

The past 20 years have witnessed major advances in BMT medicine (Lesko 1990b). BMT enables physicians to treat these diseases with aggressive chemotherapy and\or radiation by allowing replacement of the diseased or damaged bone marrow after the chemotherapy and\or radiation treatment. While bone marrow transplants do not guarantee that the disease will not recur, a transplant can increase the likelihood of a cure or at least prolong the period of disease-free survival for many patients (NYSERNet 1992). Tests are performed prior to the BMT to establish whether or not the patient has a suitable donor or not.

2.4.1 Allogeneic BMT

If the bone marrow from a donor is used, it is known as an `allogeneic' BMT. This new bone marrow must match the genetic makeup of the patient's own marrow as perfectly as possible. Special white blood cells, known as T-cells, recognise foreign matter in the body and orchestrate attacks on bacteria, viruses and other substances foreign to the body. If the donor's bone marrow is not a good genetic match, then the donor T- cells will perceive the patient's body as foreign material and will attack organs and tissues. This would impair the ability of the patient's organs and tissues to function, and would thereby increase the patient's susceptibility to infection. This condition is known as graft-versus-host disease (GVHD) and the effects can range from being mild to life-threatening. Manipulation of these T-cell populations of the donor marrow prior to infusion can greatly reduce this problem (NYSERNet 1992).

Alternatively , the patient's remaining immune system may identify the donor's new bone marrow as foreign and attack it. This is called graft rejection. To prevent graft rejection, total body irradiation (TBI) and\or chemotherapy such as cyclophosphamide are used to kill the cancerous cells and to suppress a patient's immune system. This serves to disrupt the T-cells ability to recognise the donated marrow as foreign and to launch an immune system attack. (NYSERNet, 1992).

In the case of an immunologically compatible donor being available, the donor's healthy marrow is harvested under general anaesthetic and is later infused into the patient's blood stream through the indwelling catheter. This is known as an `allogeneic transplant'.

2.4.2 Autologous BMT

If the patient has no matched sibling, then an `autologous' BMT may be considered. In this case, during remission, or if the condition being treated does not involve the

bone marrow (for example: Hodgkin's disease, non-Hodgkins lymphoma), the patient's own bone marrow is extracted under general anaesthetic, prior to the transplant. It may be `purged' to remove lingering malignant cells (if the disease has afflicted the bone marrow), and is then frozen and stored until the patient has completed further treatment and\or the `conditioning' period (final doses of chemotherapy and radiotherapy), prior to the BMT.

Autologous bone marrow transplant is complimented with stem cells which are collected from the patient's peripheral blood via a femoral catheter. This catheter is placed in the femoral vein under a local anaesthetic. The stem cells are collected after the patient's last course of chemotherapy, once the regenerated cell count is normal, and before `conditioning'is undertaken. The cells are collected in much the same way as blood is donated, between two and four times over a two hour period. The collected stem cells are stored and are re-infused together with the stored marrow through the indwelling siliconised catheter into the patient (Novitzky, N. pers.comm. 1996).

2.5 BONE MARROW TRANSPLANTATION

2.5.1 Preparation for BMT

A successful transplant requires the patient to be healthy enough to undergo the rigours of the transplant procedure. Age, general physical condition, the patient's diagnosis and the stage of the disease are all considered by the physician when determining whether a person should undergo a transplant or not.

Hospitalisation and preparation for the transplant require more tests and are accompanied by feelings of anxiety and hope (Lesko 1990b). Prior to a BMT, a battery of tests are carried out to ensure that the patient is physically capable of undergoing the procedure. Tests of the patient's heart, lung, kidney and other vital organ functions are used as a `baseline' against which post-transplant

investigations can be compared to determine any body functioning impairment. These surveillance studies are usually done on an outpatient basis.

2.5.2 The BMT Procedure

Bone marrow transplantation demands a high level of commitment and extraordinary co-operation from patients. This procedure comprises several steps, each of which makes its own psychological demands on the patient (Lesko 1990b).

The first step is to obtain a remission state. The second step involves harvesting the bone marrow. In the case of an autologous BMT, the marrow is stored and re-infused at a later date. In the case of an allogeneic BMT, the donor must be in Cape Town for a minimum of three weeks prior to the BMT. The third step is `the point of no return' (Lesko 1990b), as the patient's bone marrow is destroyed with high dose chemotherapy alone or in combination with total body irradiation (TBI). This process is known as `conditioning'and is accompanied by episodes of nausea, vomiting and fatigue secondary to irradiation and chemotherapy. The fourth step is when the patient is `rescued' with the harvested marrow, which is infused into the patient's blood stream through the indwelling catheter. The marrow finds it's way via the blood stream to the bones. The transplant is not a surgical procedure (Jackson 1994). While bone marrow is being infused, the patient is checked frequently for signs of fever, chills, hives and chest pains (NYSERNet 1992).

The two to four weeks immediately post transplantation are the most critical, as the patient's own bone marrow has been destroyed and the new marrow has yet to engraft (settle down in the marrow cavity and start to grow). The patient is therefore susceptible to infections and bleeding. Patients are supported with blood products and frequently require antibiotics for infections (Jackson 1994).

As a result of the radiation, patients frequently experience diarrhoea and mucosal

ulceration resulting in a sore mouth, throat and oesophagus which makes swallowing very painful. Under these circumstances, a naso-gastric tube is inserted for feeding purposes (Novitzky, N. pers.comm. 1996).

In a successful transplant, the new bone marrow migrates to the cavities of the large bones, engrafts and begins producing normal blood cells. A bone marrow biopsy confirms the regeneration of cells. The transplantation period requires approximately four to six weeks hospitalisation. This time period may be reduced by the effective utilisation of growth factors which stimulate the marrow to regenerate faster (Jackson 1994).

Unlike other transplants which involve solid organs, the bone marrow is fluid and is integrated into the body. Lesko (1990b) maintains that this must have implications for the patients' psychological adaptation and would help to explain why BMT patients have few of the difficulties, as experienced by kidney patients, in terms of integrating the new organ.

2.5.3 Post BMT

After a BMT, patients often express a feeling of being reborn or being given a second chance. A similar response has been noted in patients who survive a cardiac arrest and this is known as the Lazarus syndrome (Hackett, cited in Lesko 1990b).

The Haematology Department at Groote Schuur Hospital requires patients to remain in Cape Town for one year post bone marrow transplantation due to the considerable complications that may follow. Consequently, numerous patients relocate with or without their families. Those patients who relocate without their families, and who are unable to make their own private accommodation arrangements, are housed in interim homes which are run by the Cancer

Association or church organisations. Such an arrangement is fraught with difficulties as the family unit is disrupted, employment is suspended and the patient may be plunged into a period of profound uncertainty.

The rate of recovery is variable, but weakness and fatigue are invariable. Regular follow-up clinic visits are essential so that progress can be monitored and medication and\or blood products can be administered. Due to immunity and reconstitution often being slow, the patient is at risk of acquiring infections, which is one of the major complications post BMT (Treleaven et al. 1992). Contact with the general public is restricted during the recovery period and survivors are advised to avoid contact with people who have a known viral illness. Survivors can be re-infected with organisms which they have previously experienced such as measles, mumps and chickenpox. Even influenza can be a life-threatening illness for survivors (Treleaven et al. 1992). It may take six months or more, before patients are ready to fully resume normal activities.

Side effects such as cataracts, pulmonary complications, secondary malignancies, neurological and gonadal damage have been well described post BMT, but much less is known about the daily functioning of adult long-term survivors of this procedure (Andrykowski et al. 1989).

As the medical results steadily improve and patients survive disease-free, it is important to move beyond just morbidity and mortality evaluations. According to Chao et al. (1992) concerns about patients' feelings, psychological and physical fitness, functional status, and overall quality of life should be addressed. Chapter three will discuss some of these concerns.

CHAPTER THREE

PSYCHO-SOCIAL CONTEXT

The literature review of the previous chapter has clearly indicated that preparing for and undergoing a BMT is an extremely arduous process requiring fortitude. This chapter will review literature on the psycho-social implications and adaptions\adjustments of BMT survivors. Adaptive tasks and coping skills required by people undergoing a crisis will then be discussed. Although the group process is not being evaluated, it is the instrument of data collection. For this reason, the benefits of cancer support groups will be briefly discussed.

3.1 PSYCHO-SOCIAL IMPLICATIONS

Bone marrow transplantation holds the potential for either a cure or for a marked extension of survival in many instances of cancer. However, the immediate and long term psychological effects need to be considered (Derogatis 1986). Patients who survive cancer have to make the adjustment from living as a `patient' to living as a `survivor' (Lesko 1990b). Emotional stress can be associated with multiple clinic visits, lack of physical stamina, acute or chronic complications, prolonged absence from work (or school), the demands of parenting, financial constraints, marital or family discord, role strain and sexual dysfunction (Kennedy 1993). Many survivors experience the Lazarus syndrome as mentioned in the previous chapter, which involves a feeling of renewed birth. However, their emotions are often mixed, with optimism about having achieved a possible cure, combined with concern that the disease may recur (Holland 1990a). In addition, feelings of `survivor guilt' in terms of fellow patients having died, may surface. Some survivors may feel anxious about leaving the security of the hospital and feel that they are solely responsible for their own health and well-being. There may be adjustments in terms of re-entering the family as changes could have been made in their absence. Roles may have

altered and the survivor could lose out on the important activity of being a participant in the daily family experiences (Pot-Mees 1992).

Often people do not integrate the prospect of death into the concept of life. However, BMT survivors have had this task foisted on them unceremoniously. Not only do they have to cope with the aftermath of having undergone extensive chemotherapy and radiotherapy, but the continued threat of a possible relapse is a reality which survivors have to contend with. Compounding this tenuous situation is the knowledge that in the event of a relapse, BMT is considered the most intensive form of therapy available and no further treatment options exist. The challenge for the survivor is to adapt to a `new' life.

3.1.1 Sources of psychosocial sequelae

Lesko (1990a) maintains that physical and psychological convalescence after a BMT can be very stressful for patients and their relatives. Psychological convalescence is particularly difficult for those patients who have delayed or disrupted important developmental tasks.

Rowland (1990a) concurs that it is important to identify which phase of the life cycle the patient\survivor is in, whilst undergoing treatment. Rowland (1990a) in reviewing the impact of cancer on all of the life stages found that the common disruptions of illness could be divided into five categories, namely: altered interpersonal relationships, dependence versus independence, achievement disruptions, body-sexual image and finally existential issues. It was noted that the importance of a specific disruption may vary according to the stage in the life cycle and the individual concerned. Identifying the areas likely to cause stress increases the likelihood of appropriate psycho-social interventions being offered to patients\survivors. Five of the major sources of psychological sequelae that arise in

BMT survivors are identified by Tross and Holland (1990). They are discussed below and are not too dissimilar from the common disruptions caused by illness as mentioned above by Rowland (1990a).

3.1.1.1 Delayed effects of medical treatment

There is growing evidence that cancer cure may be achieved at significant risk to general physical health and psychological well being. This risk arises from the delayed physical complications of aggressive therapies for cancer known as *late effects* (Cella & Tross 1986). The first source of psychological sequelae arises from the concern about the adverse effects of treatment which often appears years later, as well as concerns about the chances of relapse versus cure (Tross & Holland 1990). The latter concern is discussed in more detail in section 3.1.1.4.

3.1.1.2 The sexual complications of treatment

The second source of psychological sequelae arises from the sexual complications of treatment which usually take two forms namely: (a) treatments that alter sexual function directly by tissue changes or indirectly by hormonal changes resulting in altered physiological function and responsivity; (b) treatments that have specific effects on gonadal function, resulting in infertility or sterility.

In a study of long term survivors of leukaemia patients treated with conventional chemotherapy alone and those treated with allogeneic BMT, Lesko et al. (cited in Lesko 1993:190) found that there was no significant difference between the two subgroups in terms of their levels of sexual desire, sexual satisfaction and body image. However, those survivors who reported decreased levels also reported greater psychological distress and decreased energy. However, compared to healthy norms, women survivors generally reported decreased sexual satisfaction and frequency, whilst both male and female survivors reported poorer body image. Greater frequency in sexual activity was predicted for females post treatment, but

poorer body images for both males and females. Lesko et al.(cited in Lesko 1993:190) concluded that these results indicate that psychosexual sequelae in leukaemia survivors occurs frequently. Wingard et al.(1992) noted that physical changes such as decreased stamina, hair loss, skin changes from graft-versus-host disease (GVHD), weight changes and scars, affect body and self image with the potential to diminish sexual functioning. Burbie and Polinsky (1992) concur with this finding.

> "Regardless of the age, marital status, kind of cancer, or types of treatment received, the challenge of coping with a cancer diagnosis often has a significant impact on the sexual and intimate relations of patients and their partners." (1992:20)

Bearing this in mind, Schover et al. (cited in Burbie & Polinsky 1992:20) argue that sexual rehabilitation does not usually require a specialised programme and should therefore, become an integral part of the cancer treatment.

Intimate relationships are affected both positively and negatively by the cancer experience. Fobair et al. (cited in Welch-McCaffrey et al. 1989:519) postulate that marital stress, which may accumulate during cancer therapy, is often temporarily put aside during the active treatment but may cause serious marital disruption on completion of therapy. In addition, side effects of treatment, such as sterility\infertility, may have an impact on marriage relationships. Shover and Fife (cited in Welch-McCaffrey et al. 1989:519) suggested that the durability of the relationship will depend on the maturity and ability of the couple to resolve such issues.

3.1.1.3 Neuropsychological late effects

The third source of psychological sequelae is the concern that central nervous system complications of treatment may result in `neuropsychological late effects' such as effects on the central nervous system and intellectual functioning. Reports

of cognitive difficulties such as reduced attention and concentration, slowed reaction time and difficulties in reasoning and problem solving were found to be common in a study of 30 adult allogeneic BMT recipients by Andrykowski et al. (1990) The extent of cognitive dysfunction was associated with the dose of total body irradiation (TBI) received during pre-BMT conditioning, even after controlling for current psychological distress, age, education and time since BMT. However, a shortcoming of this study is the fact that cognitive status was only assessed by self-report. Andrykowski (1994) found that the conclusions drawn from studies of cognitive functioning were quite limited due to their small sample size, poor or absent comparison groups, lack of long-term follow-up and\or reliance on self-reports of cognitive dysfunction. Furthermore, while a few studies suggested that long-term decrements in cognitive dysfunction might be a concern among BMT recipients, the possibility that such deficits existed prior to BMT, could not be ruled out (Andrykowski 1994).

3.1.1.4 Psychological responses to `psychic crisis'

Tross and Holland (1990) found that the psychological problems that confront the patient at the time of the initial diagnosis or during active treatment are quite different from the psychological problems that survivors face.

Cella and Tross (1986) suggest a compelling rationale for expecting `psychological late effects' after cure, based on the survivor's vulnerability to three types of stressors: `anticipatory', `residual' and `current'. The fourth and fifth source of psychological sequelae identified by Tross and Holland (1990) will be discussed below and are closely interwoven with these three types of stressors.

The fourth source of psychological sequelae is the psychological responses to having had a life-threatening illness. Tross and Holland (1990) claim that

these psychological sequelae are produced by two complementary mechanisms associated with life-threatening illness: (a) an anticipatory response to death, which is an `anticipatory' stress and, (b) a residual response to diagnosis and treatment which is a `residual' stress. These will be discussed in further detail below. The current stress will be discussed in section 3.1.1.5.

(a) Psychological sequelae are an expected result of the anticipated threat of death, arising from coming face to face with the prospect of mortality. Koocher and O'Malley (1981) maintain that even after a cure has been achieved, the survivor may anticipate a tenuous sense of longevity which may produce anxiety, depressive mood, damaged body image and fears of recurrence. This is known as the `Damocles syndrome.' Cella and Tross (1986) found greater death anxiety in survivors within two years of completion of therapy when compared with those coping with more protracted survival. Fobair and Mages (cited in Welch-McCaffrey et al. 1989:518) noted a similar finding of diminished fear over time in their study of 35 long-term survivors interviewed between three to six years after a diagnosis was made.

(b) The psychological sequelae can also be a form of residual stress syndrome, grief reaction, or traumatic disorder following the catastrophic burden of initial diagnosis. This response has been designated as the `existential plight' by Weisman and Worden (cited in Tross and Holland 1990:107) and occurs in the three months following diagnosis. It is marked by preoccupation with mortality, sense of personal vulnerability and heightened emotional distress.

3.1.1.5 Practical and social complications

This fifth source of psychological sequelae identified by Tross and Holland (1990) is the `current' stress referred to by Cella and Tross (1986). It involves the concerns

about the complications that may arise from re-entry into one's pre-morbid lifestyle.

Relationships with family and friends are often affected post BMT. Syrjala et al (1993) found that increased levels of family conflict pre-transplant was a predictor of greater difficulty with both physical and psychological recovery. Schmale et al.(1983) found that cancer survivors without significant relationships were more psychologically distressed than their counterparts who had support. A study by Northouse (1981) produced similar findings when cancer patients who were in remission and who had fewer significant supportive relationships were found to experience greater anxiety about cancer recurrence and relapse. With regard to peer support, research results by Ferrell et al. (1992) indicated a significant need for both the patient and the family to have peer support. Furthermore, this need was evident across all phases of bone marrow transplantation, beginning with the need for information pre-transplant and extending through to the need for support and understanding during the long-term rehabilitation and adjustment to life as a bone marrow transplantation survivor. Visits by survivors of BMT, who were able to share their recovery with new patients undergoing a BMT, were often found to be an important source of support (Lesko 1993).

Maher (1982) found that survivors were most in need of interpersonal support after the completion of treatment, but that they frequently found it unavailable, particularly if they did not look ill. This may be due in part, to the family members having exhausted their ability to give support during the survivor's active disease phase. According to Welch-McCaffrey et al. (1989) the task of being supportive while containing their own anticipatory fears about the survivor's condition is a difficult one. The tendency of survivors to protect their families' emotional state was reported by Woods and Earp (1978) who found that survivors were aware that they triggered emotions in family members by talking about their fears. As a consequence, they refrained from doing so, which in turn, promoted

`conversational isolationism'. The mere fact of having a diagnosis of cancer may be an isolating experience. (According to Welch-McCaffrey et al. 1989) The phenomenon of isolationism for cancer survivors has a dual manifestation in that isolation by others implies an external cause, whereas self-isolation indicates an interpersonal source of conflict. Forming new relationships and anxieties about the degree of disclosure in terms of the past history of cancer may also be a major concern for survivors. Welch-McCaffrey's (cited in Welch-McCaffrey et al. 1989:520) study identified the major stressors for the unmarried survivors as concerns about sterility, explanations during courtship, and finding partners accepting of the cancer history once the diagnosis was disclosed. Cella and Tross (1986) found that survivors were less inclined toward intimacy, suggesting a relationship between the cancer experience and the ability to engage in warm, interpersonal relationships. Thus a history of cancer may increase the survivor's sense of social isolation.

Poorer health or physical disability affects not only the transition into social and interpersonal relationships, but also the transition into the work environments. It may require the re-evaluation of existing goals and the reformulation of new life goals. A study by Andrykowski et al. (1989) of survivors who were 52 months post BMT, found that most survivors had achieved a ceiling level of functioning within two years. Lesko (1990b) found that both physical and psychological convalescence usually takes a year. Syrjala's et al. (1993) study concurs with the above findings. In their study functioning was most impaired 90 days post BMT. However, the majority of survivors were functioning well both physically and psychosocially within a year. Nevertheless, the majority had not returned to full-time occupations or activities at the end of the first year. Those survivors who had not regained adequate functioning within the first year, could anticipate additional recovery in the levels of stamina and physical functioning occurring between one and four years with most recovery accomplished by two years post transplant.

Ninety per cent of the survivors in their study had returned to full-time occupations after four years.

3.1.2 Psychological impact

3.1.2.1 Impact on self concept

Koocher and O'Malley (1981) observed that although cancer survivors are essentially free of undue levels of gross psychopathology and are capable of functioning effectively in social-interpersonal roles, subtle differences in self-concept, motivation, and sense of being-in-the-world are apparent. Although there is evidence that these effects lessen with time, Cella and Tross (1986) report that patients who survive cancer, experience a noticeable existential disruption which they relate directly to their illness. Tross and Holland (1990) found that early studies of psychological functioning generally indicated an absence of clinical psychiatric disorders or discrete functional impairment. However, mild psychological concerns in survivors may be evident, with a greater sense of vulnerability, higher levels of anxiety and depression, diminished sense of control, fear of social rejection, and a sense of personal inadequacy.

3.1.2.2 Impact on mood

According to Lesko (1990b), depression and chronic anxiety are the most common psychiatric sequelae of the transplantation procedure. Andrykowski et al. (1989) supported this finding when they established that BMT survivors evidenced greater mood disturbance relative to samples of testes cancer survivors, patients with lung cancer and patients with metastatic breast cancer. Age was significantly related to post BMT outcome, with transplant patients below 30 years of age reporting significantly better functioning on physical and social dimensions and less mood disturbance than their older counterparts. This finding was consistent, irrespective of the time lapse since the transplant.

3.1.2.3 Impact on energy levels

The interrelationship between physical and psychosocial sequelae experienced by survivors is often underestimated. Fobair et al. (cited in Welch-McCaffrey et al. 1989:522) found energy loss to be correlated with both clinical depression and age in survivors of Hodgkin's disease. Patients under 34 years had a return of energy within one year after therapy, whereas older patients required longer recovery periods. Wellish (cited in Welch-McCaffrey et al. 1989:518) commented that survivors older than 34 years are more likely to experience physical compromise, such as exhaustion, during the early part of their illness and recovery, and are less likely to have psychological problems. Conversely, younger survivors may initially experience more psychological problems with less physical distress. According to Welch-McCaffrey et al. (1989) physical and psychological indicators of well-being during survivorship merit joint study. As there is a link between the physical and the psychological aspects, it would increase the understanding of this dynamic relationship.

3.1.3 Seasons of survival

In addition to scientific investigations, another source of information is from the survivors themselves, who are willing to describe their personal responses to cancer and BMT. Mullan (1985) described psychological reactions to three periods after treatment that he called the `seasons of survival': `*Acute survival*' begins with the diagnosis of the illness when patients are forced to confront their own mortality and begin to make adjustments that will be part of their immediate and, to some extent, long term future. Fear and anxiety are usually constant elements of this phase. This phase is dominated by cancer treatment and it's side-effects to which the patient has to adapt. `*Extended*' survival begins during the remission period

when a cure is hopeful yet uncertain. Psychologically, this period is dominated by fear of recurrence of the cancer. Survivors are required to make adaptions in terms of re-entry into their family, society and their work environments within the constraints of possible physical limitations. This may necessitate changes in personal and vocational roles. During this phase, feelings of depression, anxiety and isolation are not uncommon. The final phase of adaption is referred to as,*'permanent survival'*.

> *Cure*. The word itself became magic for me, a time when everything would be all right again, when the shadow in my life would be gone, when normal life would resume." (1985:271)

Mullan (1985) argues that the experience leaves a physical and emotional impression on the person, regardless of the fact that he\she has achieved `permanent survival'. Difficulties with employment and insurance may continue to be problematic during this phase. Furthermore, the long-term secondary effects of treatment, such as the effects of chemotherapy and\or radiotherapy on the reproductive functioning, may be an underlying or overt concern for the survivor. It is apparent from the `seasons of survival' framework as suggested by Mullan (1985), that the issues facing survivors vary, according to the particular phase they are in. This concept is supported by Tross and Holland (1990). Derogatis (1986) postulated that the psychosocial impact of cancer survivorship lessened with time. Hence, duration from diagnosis and completion of therapy should be considered when evaluating the psychosocial status of survivors.

In order to promote healthy survivorship Mullan (1985) suggests that cancer patients should be educated in terms of: (1) anticipating fears of relapse, (2) adjusting to living with compromises entailed by treatment, (3) the emotions of

anger (about compromise), anxiety and depression, (4) the need to self-monitor for physical symptoms (but not become pre-occupied) and (5) the need to become part of a community of survivors (to offer a network, information and support).

3.2 ADJUSTMENT AND COPING SKILLS

3.2.1 Adjustment and adaption

Patients who are diagnosed with cancer have to make many adjustments which may be facilitated or impeded by the health care system. For example, in the past, it was taboo to disclose a diagnosis of cancer to patients in the belief that it would distress them and negatively influence their ability to cope (Holland 1990b). However, of late, there has been a marked shift within medical circles to openly communicate the diagnosis and prognosis with patients and their families, and to include them in the treatment decisions. With the conspiracy of silence broken, open communication enhanced the sense of trust between patients and their caregivers (Holland 1990b). One of the most difficult tasks for the physician is to supply complete information while respecting the patient's right to deny the situation. Providing information is an important part of relieving anxiety, but providing the information at a rate that is manageable for the individual patient reflects the art of medicine (Silberfarb 1988). The giving of information is therefore, a complex task.

Adjustment to cancer is not an isolated occurrence. Instead it is affected by our environment. Rowland (1990a) refers to the three broad variables that influence the psychological adjustment of patients to cancer: The *socio-cultural context* refers to the social attitudes and cultural beliefs about cancer, which can affect not only how patients and their families are treated, but also how they view themselves, their illness and their future. The *medical context* encompasses the stage of disease being treated, the type of treatment being used and the particular site or sites affected. The *individual psychological context* applies to the developmental stage, the intrapersonal style and the interpersonal resources of the patient. In the

researcher's opinion, the existential\spiritual aspects are also of primary importance as patient's are facing issues of mortality.

Although there are many different perspectives on what constitutes coping, there has been a general shift away from a view of human beings as being under siege, to an adaptational view of human beings, in which life's stresses are seen as challenges or tasks to be mastered through thoughtful use of available social and psychological resources (Rowland 1990b).

According to Slaikeu (cited in Burbie & Polinsky 1992:21) the four tasks of crisis resolution include physical survival, expression of feelings, cognitive mastery and behavioural\interpersonal adjustments. In addition, the framework outlined by Moos and Tsu (1977) which is outlined in the following paragraph, understands serious physical illness as a life crisis. It is therefore, relevant for understanding the adaptions to the crisis of having cancer and will be presented in some detail.

According to Moos and Tsu (1977) background and personal characteristics, illness related factors, and features of the sociocultural environment all affect psychological adjustment and may determine the outcome of the crisis. These are not dissimilar from Rowland's (1990a) (mentioned in section 3.2.1.) factors which may affect psychological adjustment.

The major adaptive tasks outlined by Moos and Tsu (1977) are divided into seven general categories. Three of these categories are mainly illness related and include (1) dealing with pain and incapacitation, (2) dealing with the hospital environment and special treatment procedures, (3) developing adequate relationships with professional staff. The remaining four are more general and are relevant to all types of life crises and include (4) preserving a reasonable emotional balance, (5) preserving a satisfactory self image, (6) preserving relationships with family and

friends and (7) preparing for an uncertain future.

In terms of the adjustment of BMT survivors, Taylor (cited in Rowland 1990b:48) identified three themes, namely, a search for meaning, an attempt to gain mastery over the event, and an effort to enhance one's self-esteem. These three themes concur with aspects of the abovementioned framework as outlined by Moos and Tsu (1977).

Silver et al. (1993) highlight the fact that the ability to find meaning in a major negative life event may be an important factor in subsequent psychological adjustment to that traumatic event. Silver et al. (1993) in a study of incest victims found that:

> `To the extent that the search for meaning results in finding meaning in an undesirable life event, it is likely to be an adaptive process. We maintain that the ruminations and cognitive rehearsal that accompany such a search serve an adaptive function in that they are likely to be the means by which individuals gain mastery over and make sense of their experience. However, finding meaning does not appear to terminate the search or the ruminations. Moreover, when after an extended period the search fails to bring understanding, the continuing process of searching and repeatedly ruminating appears to be maladaptive.' (1993:96)

3.2.2 Coping

Common themes emerge from the body of coping research and adaptation to cancer. Firstly, styles that promote an active response to problem solving and coping behaviour are the most effective for coping with cancer. Secondly, coping with illness is a dynamic process, changing as a function of the circumstances and of the individual's continuing appraisal of its meaning with respect to his\her survival, future, relationships, self-esteem, and achievement of goals. Thirdly, people who are flexible in their efforts are better able to cope. Finally, the nature and amount of social support available to the individual strongly influences his\her ability to cope (Rowland 1990b).

Thus it would seem to follow, that the patient's ability to master the treatment phase would influence his\her ability to master the adaptation phase. However, Tross and Holland (1990) stated that the debate on whether the delayed psychological effects of cancer and it's therapies accompany the patient into the cure period continues. Tross and Holland (1990) argue that the answer may be gradually emerging as more individuals survive cancer and are studied for both general psychosocial function and more subtle forms of psychological impairment.

According to Moos and Tsu (1977) the types of coping skills which would assist the adaption to cancer include the ability to: deny or minimise the seriousness of a crisis, seek relevant information, request reassurance and emotional support, learn specific illness-related procedures, set concrete limited goals, rehearse alternative outcomes, and find a general purpose or pattern of meaning in the course of events. The last coping skill is supported by Blazer et al. (cited in Rowland 1990b:47) who suggest that higher levels of self-reported well-being is associated with religious convictions and beliefs.

These skills may be used individually, consecutively, or in various combinations. The point being made is that specific coping skills are not inherently adaptive or maladaptive. Furthermore, skills that are appropriate in one situation may not be in another.

3.2.3 Positive change

It is evident that having cancer and living as a survivor of that disease has enormous repercussions for the individual, his\her partner, family and friends. The challenge is to cope with and adapt to these repercussions. It is however, important to be aware that survivors also experience positive changes as a result of having cancer. In a study of 133 individuals with malignant disease who were undergoing

evaluation for BMT, positive and negative psychosocial, physical, and functional changes following the diagnosis of cancer were assessed. Andrykowski et al. (1993) concluded that:

> `While malignant disease can clearly be associated with a multitude of significant negative sequelae, it is not a stressor with uniformly negative outcomes. Rather, cancer might profitably be viewed as a "psychosocial transition", i.e. an event with significant negative implications that can nevertheless cause individuals to restructure their attitudes, values and behaviours, and thus can serve to trigger positive psychosocial change. Clinical work with cancer patients should thus reflect the twin goals of minimisation of distress as well as capitalisation upon an enhanced likelihood of growth and positive life change.' (1993:274)

This statement is supported by Welch-McCaffrey et al. (1989) whose study noted a host of `secondary benefits,' resulting from a diagnosis of cancer, including strengthening of the family unit, a greater appreciation of life, increased satisfaction with life, increased self-acceptance, and a renewed interest in religion. An important role of the social worker working with cancer patients and survivors is to be aware of and acknowledge problems as well as benefits.

3.3 CANCER SUPPORT GROUPS

In this study, the group was the instrument used to collect data. As the members' assessment of the value of the group was obtained, it is useful to look at cancer support groups and their value.

According to Vugia (1991) support groups primarily focus on helping members cope with a homogeneous problem. Wandersman (1982) and Wasserman & Danforth (1988) (cited in Vugia 1991:94) basically describe the objectives of these groups as follows: To provide positive reinforcement and encourgement to members; to respect individual styles, needs and values; to share information that could enhance members' coping skills; to discuss advantages and disadvantages of various coping methods that members or the leader offer. Furthermore they suggest

the professional leader's role is to provide cohesive planning, structure and information; help build mutual aid and prevent group casualties.

Types of group interventions for cancer patients have been proposed by Weiss (cited in Vachon 1994) whose model takes into account the life changes that divide adaption to cancer into three stages: crisis, transition and adjustment\reconstruction. Particular types of interventions are considered appropriate for each stage.

Weiss (cited in Vachon 1994) suggests that during the crisis period of adapting to a stressful life change an individual is often stunned and numb, with disorientation, distraction and\or fight or flight reaction. At this point the person has no energy to do anything other than accept the support given. Help will usually need to be directive.

According to Weiss (cited in Vachon 1994) group intervention during the transition phase is characterised by preoccupation with the past and mourning for a world that has been but is now altered. During this stage there is often anger, anxiety, depression, guilt and shame. Group meetings can serve to provide cognitive input and provide a framework that puts the individuals experience into perspective. Group members with a similar `identity' are often helpful for one another.

Weiss (cited in Vachon 1994) refers to the establishment of a new identity as someone who has lived through the experience of having cancer and can now begin to face the future. This is the final stage of adapting to a stressful life event. For some people this new identity involves moving beyond the experience and seeing oneself as someone who has or has had cancer but has many other aspects to one's life. As the normalisation process takes place it is often beneficial for group members to gradually move out of the open-ended group or else to become a

volunteer who acts as a role model to other patients. For others the new identity involves what Weiss calls a `deficit situation' wherein one is defined primarily in terms of the stigmatised identity. In this scenario there is a tendency for survivors to become involved in long-term affiliation with members of the stigmatised group rather than moving beyond the cancer experience. This support network can provide support for dealing with the inadequacies they feel in their lives.

Research on the use of support groups for cancer patients frequently supports and confirms benefits of the group experience for these patients. Examples include the work of Spiegel et al. (1981) who assert that the premise of the cancer support group is that sympathetic and direct confrontation with life-and-death issues results in mastery rather than demoralisation. The group setting provides emotional support, enhances the patients' repertoire of coping strategies, and diminishes his\her sense of isolation, helplessness and worthlessness. Findings by Forester et al. (1993) supported this when weekly group psychotherapy sessions succeeded in reducing the levels of emotional and physical symptoms in patients undergoing radiotherapy. Furthermore Ferlic et al. (cited in Spiegal et al. 1981:527) studied thirty patients with advanced cancer who were given six group-therapy sessions and were compared with 30 matched controls. There was an improvement in self-concept, hospital adjustment, knowledge about cancer and the ability to explore death-related issues. Ferlic et al.'s study (cited in Spiegal et al. 1981:527), although limited by the lack of follow-up data, provides some clinical evidence that group interventions can be helpful.

The primary focus of this study is not on examining the process of a support group. However, the subjective experience of the group members regarding the usefulness of the group in helping them to cope with some of the issues they identify will be commented on.

In the next chapter, the research methodology used in this study will be outlined.

CHAPTER FOUR

METHODOLOGY

In this chapter, the aim of the study and research design, sampling, the process of data collection, method of analysis and the limitations of the study will be discussed.

4.1 AIM OF THE STUDY AND RESEARCH DESIGN

The aim of the study is to gain a better understanding of the problems experienced by BMT survivors, as well as their perceptions of how the cope. Therefore, in this study an attempt will be made to conceptualise the experiences of BMT survivors from their own subjective perspective. A further aim is to obtain an evaluation of the group by the members. An exploratory study using the qualitative method with it's emphasis on the internal subjective world of the people under study was therefore the most suitable approach.

4.2 METHODOLOGICAL ISSUES

According to Bryman (1988) two major theoretical perspectives have dominated the social sciences arena namely, positivism and phenomenology.

The positivists and the phenomenologists interpret the role of the researcher differently. While the natural scientist has nothing in common with his\her research objects (plants, gases etc), the social and behavioural scientist is in reality a member of what is being studied. The phenomenologists believe that human behaviour cannot be understood without appreciating the context in which it takes place. Although the meaning of human existence is not equated with its context, it cannot be separated from it. Contrary to this, the positivists are searching for

universal, context-free generalisations (Huysamen 1994).

In terms of the aims of the research the positivists aim at uncovering general laws of relationships and\or causality that apply to all persons and at all times, whereas the phenomenologists are concerned with understanding social and psychological phenomena from the perspective of the persons involved. With regard to the research design and methods the positivist approach requires that a research design is finalised before one commences with data collection, while the anti-positivists usually favour so-called emergent designs. This means that the researchers may adapt their data-collection procedures during the study to benefit from data which they have become aware of only during the reseach process itself (Huysamen 1994).

Babbie (1992) argues that since positivists and phenomenologists take on different kinds of problems and seek different kinds of answers, their research demands different methodologies. Thus, the positivists search for potentially `causal' associations through quantitative methods such as questionnaires, inventories and demography which produces data amenable to statistical analysis. The phenomenological approach seeks understanding primarily through qualitative methods such as participant observation and in-depth interviews which yields descriptive data.

According to Ely et al. (1991) qualitative methodology broadly refers to research which produces descriptive data of people's own written or spoken words and observable behaviour.

Qualitative research is inductive, following a relatively flexible research approach which allows for insight and understanding to be gleaned from patterns in the data (Taylor & Bogdan 1984). The researcher will need to set aside his\her own beliefs

(Lofland & Lofland 1984) and attempt to empathise and identify with the people studied (Bass et al. 1993). The researcher would also be a participant observer, which inevitably has some influence on the group.

A qualitative approach was chosen by the researcher as it gave expression to the lived world of the survivors. It elicits relatively rich responses and allows one to delve deeper and unearth hidden meanings. However, it should be noted that this was a support group as opposed to a psycho-therapeutic group. Therefore, meanings were not analysed in depth but were more descriptive in nature.

4.3 POPULATION AND SAMPLE

The total number of BMT survivors of the Haematology Department of Groote Schuur Hospital between the period 1988 to 1995 was 113 members. Survivors were required to fulfil the following criteria: those who were over 18 years old, not in relapse, had a working knowledge of English\Afrikaans and who lived in the city of Cape Town and the surrounding areas. A total of 27 survivors fulfilled the above-mentioned selection criteria and were invited to join a support group by way of a written invitation which included a self-addressed stamped envelope and a reply slip. The purpose of the group, practical information, details in terms of the professions of the facilitators, and that the group proceedings would be documented as a part requirement for a Masters Degree were discussed. Prospective members were requested to make a commitment to attend at least eight consecutive sessions.

Fourteen replies were received of which seven survivors wished to join the group. Prior to commencing the group, those survivors interested in attending, had the opportunity to discuss any individual and group concerns with one of the two facilitators. Patients who were having their transplants after the groups' formation, were encouraged by the facilitators and the doctors to join the group.

4.4 PROCESS OF DATA COLLECTION

An open support group which offered a combination of educational, supportive and psychological interventions was run fortnightly for one hour at the Cancer Care and Resource Centre which has no affiliation to the Groote Schuur Hospital.

The 15 group sessions were facilitated by a female social worker and a male psychologist using group work principles. The latter assisted with validating the data and minimising bias. The co-facilitator served the function of independently generating themes which matched the themes identified by the researcher.

The groups followed an open non-directive format with the members introducing the topics or issues of their choice. All of the sessions were tape recorded and transcribed. The final session was utilised for evaluation of the group by the members.

4.5 DATA ANALYSIS

According to Marshall and Ross (1989) qualitative data analysis refers to the search for general statements about relationships among categories of data. It is the process of bringing order, structure, and meaning to the mass of collected data.

Miles and Huberman (1994) outlines three distinct phases in the analysis of qualitative data. The first phase involves data reduction which refers to the process of organising the data by selecting, structuring and ultimately transforming the data.

Miles and Huberman (1994) point out that reduction of data needs to be regarded as an ongoing part of the analysis process. The second phase involves generation of themes and is often regarded as being both a complex and creative part of the analysis. It requires that the researcher be highly aware of the data and be focused

in his\her approach in order to identify salient themes, patterns and categories. The third phase requires the researcher to search for alternative explanations in order to critically challenge the patterns which emerge from the data.

This above-mentioned three phase procedure was adopted in the analysis of the data in this study. Firstly, the mass of data emanating from the groups was organised into specific areas of focus Thereafter, themes around these specific areas were identified and analysed. Finally, the researcher searched for alternative explanations by grounding the emerging themes within the BMT context.

4.6 LIMITATIONS OF THE STUDY

BMT is a relatively new procedure in South Africa, therefore the client population is small. The primary limitation of this study is related to the lack of generalisability due to a) the research design, b) the small sample and c) the lack of representation across population groups. While an attempt was made to improve validity by the use of a co-facilitator, who attended the groups and monitored the analysis, limitations in this area should be noted. A further limitation was that the linguistic criterion excluded participation in the study of survivors who were not able to understand English or Afrikaans. Thus this resulted in the group not being representative of all races. A further limitation was that the majority of the members were from middle class backgrounds, thus reducing perspectives across social class.

In the following chapter the findings of the study will be presented and discussed in greater detail.

CHAPTER FIVE

PRESENTATION AND DISCUSSION OF FINDINGS

A few comments on the group sessions and membership will introduce this chapter. Thereafter, the process of the data analysis will be described. The findings will then be presented and discussed according to clusters of problems which were identified by the members, their experience of these problems and how they coped with them. In certain instances, the benefits of the group experience for the members will be commented on.

5.1 CHARACTERISTICS OF THE GROUP

This group formed part of an ongoing open support group. The study focused on 15 sessions that were run fortnightly for the duration of one hour. As mentioned in the previous chapter, a female social worker and male psychologist were the facilitators. Except for initial introductions, the leadership style was non-directive. The group developed as a support group rather than a therapeutic group which would have focused on emotional and behavioural change. The common bond of the BMT experience allowed the members to engage with one another easily. This facilitated cohesion and trust and enabled members to participate freely with one another.

The group initially started off with four members. As it was an open group, eight more members fulfilled the selection criteria. Thus this study focused on a total of 12 people (refer to table III). There was an equal distribution of men (n=6) and women (n=6) which was coincidental. Their ages ranged from 22 to 66 years old. A working knowledge of English or Afrikaans was required in order to be able to participate in the group. Consequently this precluded those persons who did not speak English or Afrikaans. With the exception of one coloured member, all the

members were white. The majority of the patients were from middle-class backgrounds.

Table III GROUP POPULATION

		Number
GENDER	Male	6
	Female	6
AGES	20-30	4
	31-40	2
	41+	6
PREVIOUS DIAGNOSIS	Leukaemia	6
	Lymphoma	5
	Myeloma	1
YEARS SINCE BMT	-1	7
	1-2	2
	2-5	1
	5+	2
RESUMED WORK/STUDIES	Yes	6
	No	6
ABODE	Local	8
	Up-country	4

5.2 GROUP PROCEDURE

Lack of attendance amongst the group members varied for a number of reasons including admissions to hospital, relocation, alternative commitments and group attrition (refer to Table IV). The researcher is aware that while members may have perceived the issue under discussion as problematic, they may have chosen not to acknowledge it for differing reasons. Alternatively, group members may have been absent during a specific group and thus their input would not have been recorded. Therefore, lack of total responses is reflected in the tables which will be referred to in this chapter (refer to Tables VI-XIII in text and Tables XIV-XVI in Appendix A).

The focus of the study was not on group process. Concrete topics such as the need for information, which had an external focus were discussed in the earlier phase of the group. Once members had established trust and rapport, more emotionally laden topics requiring a certain level of introspection, such as infertility and loss of relationships, were then raised. Although the group was ongoing, the end of the 15 sessions coincided with the group's decision to break for the summer vacation period. Therefore, only 15 sessions will be used for this study.

Table IV ATTENDANCE AT GROUP SESSIONS

	Members											
Sessions	1	2	3	4	5	6	7	8	9	10	11	12
1	*	-	*	*	-	*	*	-	-	-	-	-
2	R	*	*	A	-	A	A	*	*	-	-	-
3	R	*	A	*	-	*	*	A	*	-	-	-
4	R	A	*	A	-	*	*	*	A	-	-	-
5	R	A	*	*	-	A	*	A	A	-	-	-
6	R	*	*	*	-	*	*	A	*	-	-	-
7	R	*	*	*	-	*	*	A	*	*	-	-
8	R	*	*	*	*	*	*	*	T	A	*	-
9	R	*	*	*	*	A	*	A	T	A	*	-
10	R	*	A	*	A	*	*	*	T	A	R	-
11	R	*	A	*	*	*	*	*	T	*	R	*
12	R	*	A	*	*	A	*	*	T	*	R	*
13	R	A	*	*	R	*	*	A	T	*	R	*
14	R	A	*	A	R	*	*	A	T	*	R	*
15	R	*	*	A	R	*	*	*	T	*	R	*

- indicates prior to joining
* indicates attendance
A indicates absence, apologies submitted
R indicates relocation
T indicates termination

5.3 PROCESS OF DATA ANALYSIS

The following format was used in analysing the data: Tape recordings of the 15 sessions were transcribed. The contents of each session were analysed in terms of self-identified problems, the coping mechanisms and the value of the group

experience for the members. Twenty four themes were identified around these areas. These were divided into seven themes and seventeen sub-themes. A list was made of all the themes and sub-themes according to (a) which group sessions they were discussed in and (b) how common they were. This enabled the identification of when a particular problem\theme was mentioned in terms of the group development. It identifies which themes were recurrent and gives an indication of the extent of the problem (refer to Table V). Each theme was then recorded against every group member thereby giving a guide as to how many members considered a particular issue to be a problem within the group (refer to Tables VI - XIII in text and Tables XIV - XVI in Appendix A).

TABLE V THEMES OF SELF - IDENTIFIED ISSUES OF BMT SURVIVORS

THEMES		GROUP SESSIONS														
	GROUP SIZE	1 (5)	2 (4)	3 (5)	4 (4)	5 (3)	6 (6)	7 (7)	8 (8)	9 (6)	10 (5)	11 (6)	12 (7)	13 (6)	14 (5)	15 (7)
SUPPORT		***** **		*		*		**	*	*		**	*	*	*	
PRIOR NEED TO MEET BMT SURVIVORS		*		*****		*		***								
INFORMATION		*		**	*****			**	***			*				
SELF-IDENTIFIED EMOTIONAL STATE	DEPRESSION			*							*		*	***	*	
	ANXIETY			***	***	*	*****	*	**	**		**		**	*	
	STRESS					***			*	**	****	*		***		
LOSSES		***** ***	****	***** *	****	**	*****	***	**	***	*****	*****	***** *	***** ***	***** **	
SELF CONCEPT	POSITIVE	*				**	***	*	*		*	**		*		
	NEGATIVE	*				***		**			*	***	*	*****	**	
FEAR	INFECTION								***							
	RELAPSE								****			**				
	DEATH			*												
GUILT					*	*	**	*	*	*				*	**	
ANGER	SELF											*		*		
	STAFF				***											
	OTHER	*						*					*	**	*	
SOCIAL	INTERACTION	**				*				*****			**	*		
	WITHDRAWAL	*								***			*	**		
RELIGION			***	*	*	*	*			*					*	***
COPING		*				***	***	**	***	**	*	**	*	***		

* indicates the number of times an issue was raised

5.4 FINDINGS

Whilst many themes emerged, due to the time constraints of this study, only the predominant problem areas identified by the members will be discussed. Some of the findings will not be discussed and will only be presented as tables (refer to Appendix A). The discussion of problem areas closely resembles the order in which they were raised in the group (refer to Table V). It should be noted that there may be an overlap of themes as one frequently influences\leads to the other and visa versa. The findings will also mention how the problem was experienced by the members and how they coped with it. As mentioned in some cases, the benefits of the group experience will be commented on.

5.4.1 Prior need to meet BMT survivors and the need for more information

Table VI PRIOR NEED TO MEET BMT SURVIVORS AND THE NEED FOR MORE INFORMATION

	Members											
	1	2	3	4	5	6	7	8	9	10	11	12
MORE INFORMATION	-	-	-	-	-	-	*	*	-	-	*	-
MEET SURVIVORS	*	*	*	*	-	*	*	*	*	-	*	-

* indicates positive response
\- indicates no acknowledgement/absent during discussion

The prior need to meet survivors was discussed in over half of the group sessions (refer to Table V). Two thirds of the cohort wished that they had been able to meet BMT survivors before their transplant (refer to Table VI). It was felt that it was important to physically see a survivor who would be able to share their personal testimonies with them and answer their questions. The members felt that meeting

other survivors would be a source of inspiration.

In terms of information less than half of the members felt that they required more information (refer to Table VI). However, one member felt that although the information was available, the explanations were too advanced for him to grasp. There was also a feeling that information was their right and that staff should not be paternalistic. This is clearly illustrated by member 8's comment:

> `Although I acknowledge that nowadays people get told a lot more than they did in the past, the whole idea of not telling people because you know what is good for them seems to go the whole way through.'

This was echoed by member 6 who was very angry about staff withholding information about her sister's death until later in the evening, when family members were available to support her. Some anger was expressed about not being listened to, in terms of a request for information as is clearly demonstrated by member 3's comment.

> `It is easier to cope with something if you know what to expect. I asked the doctor to give me a few days warning when I needed to have a bone marrow biopsy. This didn't happen. I burst into tears, I was so angry and upset because he hadn't listened.'

The question of how much detailed information to tell people was also discussed. There seemed to be some ambivalence around this topic as is seen by the following two comments by members 7 and 8, respectively.

> `You can tell some people everything and be very open, but there are still some folk that would go to pieces if you told them everything.'

> `Some people are angry when they are not told, but if they had been told at the time they would have cracked up.'

Member 8 also acknowledged that it was possible that he was unable to hear

information because he might have been too anxious. Member 7 expressed the opinion that too little information post BMT was available.

Discussion: As noted the retrospective need to meet BMT survivors prior to their own transplant was high. It appears that a `survivor' was a symbol of hope in terms of their own struggle. Moreover, there appeared to be a need to find out about the BMT experience from a layman's point of view. This finding strongly re-inforces the suggestion by Lesko (1993) that current BMT patients require the support of survivors.

In terms of information, three members felt the need for more information. This was not significant in the group which is possibly a reflection of the policy of open communication and family meetings in the Department of Haematology at Groote Schuur Hospital. However, as this topic was raised relatively early in the group, the researcher takes into account the possiblity that members had reservations about being `critical' of the department that had been instrumental in saving their lives. Moreover, the facilitators were themselves members of the Haematology Department, and although the expression of anger was encouraged, members may have found this difficult. It was apparent that the members understood the complex nature of the giving and receiving of traumatic and highly evokative information. However, the general concensus in the group was that open and honest communication is preferable. This supports Holland's (1990b) view that open communication enhances trust between patients and their caregivers.

5.4.2 Self-identified emotional states

Self-identified states refers to feelings of depression, anxiety and stress as identified by the members themselves.

Table VII SELF-IDENTIFIED EMOTIONAL STATES

	Members											
States	1	2	3	4	5	6	7	8	9	10	11	12
DEPRESSION	-	-	-	*	-	-	*	-	-	-	-	*
ANXIETY	-	*	*	*	*	*	*	*	*	-	-	*
STRESS	-	*	*	*	*	*	*	*	-	-	-	*

* indicates positive response
- indicates no acknowledgement/absent during discussion

5.4.2.1 Depression

This issue was raised in less than half of the groups (refer to Table V). Only three of the members reported having intermittent feelings of depression and\or moodswings (refer to Table VII). One member was on a course of anti-depressants. Member 6 shared that she felt miserable and depressed if she was not productive. She felt that she needed a purpose in life and thus started a business from home. Member 7 attributed his feelings of depression to feelings of guilt. This will be discussed in more detail under the theme of guilt (refer to section 5.4.6.).

Discussion: Fobair et al (cited in Welch-McCaffrey, et al 1989) found that energy loss correlated with both clinical depression and age in survivors of Hodgkins disease, with survivors over 34 years old requiring longer recovery periods. Although this applies to one patient it is not significant in terms of the number of members in the group. Although Lesko (1990) found that the incidence of depression ranks side by side with anxiety as the most common psychological sequelae of BMT, this was not evident in this group.

5.4.2.2 Anxiety

This was a strong theme that came up in the most of the sessions (refer to Table V). Anxiety was a problem for three quarters of the cohort, one of whom suffered from panic attacks post BMT (refer to Table VII). Two of the members admitted having nightmares which started after their BMTs and continued for a few weeks. Anxiety was experienced in relation to work and social situations. The latter is well illustrated by member 9's observation:

> `I don't feel anxious when I am at home. I have done the same work for 34 years without a problem, but if I know that I have to go to work I feel so anxious for the preceeding day and evening and I can't cope in the job. I have attempted to work, but the anxiety is so overwhelming that I no longer go to work.'

Coping was difficult as the anxiety caused many of the patients to lose self-confidence as is revealed by member 3's remark: `I was so scared of being responsible for fear of causing an accident, that I didn't drive my car for some time.' Member 2 felt anxious about leaving her home and delayed doing so until the last possible moment. She related her anxiety to fear as is highlighted in her statement:

> `I feel that anxiety is related to fear. Fear of failure, the future, just fear. Once you feel vulnerable you become even more anxious and avoid situations.'

Discussion: Three quarters of the group members reported feeling anxious, which supports the findings of Lesko (1990), Tross and Holland (1990) and Andrykowski et al. (1989) who found that anxiety was a common sequelae post BMT. Anxiety seemed to pervade many aspects of the member's lives and included concerns about the future, health, interpersonal relationships, sexual functioning, infertility and social and occupational functioning. The nightmares experienced by two of the members may indicate unresolved issues or an underlying anxiety. Although neither of these members were able to recollect the content of their nightmares, they remembered waking up feeling anxious and tense.

5.4.2.3 Stress

The issue of stress was raised in over half of the sessions (refer to Table V). Two thirds of the group reported high levels of stress, (refer to Table VII), which was multi-factorial and included their inability to achieve previous levels of functioning, difficulties with occupational and social adjustment, feeling isolated, and having to remain in Cape Town post transplant.

It was also a result of trying to compensate for lost time. This is illustrated by member 2's comment that:

> `I allow myself to get too stressed out because I want to do too much. I am forever on the go as I feel that I have lost an enormous amount of time because I was ill for so many years.'

Stress was also experienced by three members who felt unable to share their fears or concerns with loved ones as they did not want to alarm or upset them. One member acknowledged stress as a result of not having anyone to talk to about his concerns.

One member felt less able to adapt to change since the BMT. Members tended to deal with stress in a variety of ways. Member 2 bottled up his frustrations while member 3 said: `I try not to let things get to me, but I do tend to block it out rather than deal with it.' Member 4 commented `I confront issues straight away. I need to get things off my chest. A good cry often helps.' Other forms of coping with stress involved making conscious decisions to take time out of their busy schedules for rest and relaxation which included reading, going on walks, attending gym and taking leisurely baths.

Discussion: Rowland (1990a) suggested that being diagnosed with cancer, receiving treatment and undergoing a BMT results in major disruptions in the lives of

survivors. Similar findings were evident in this study as re-entry into society was experienced as stressful for the majority of the survivors. The stress appeared to be particularly increased for one member for whom the treatment had lasted several years. This has had a major impact on her self-esteem, her ability to socialise and her occupational functioning. As a direct result of the BMT she was unable to utilise her qualification and pursue her chosen career.

Despite survivors' stated need for open communication, it was found that communication between family members and the survivor was lacking. Some of the members admitted that they did not like to discuss concerns about their health with their family for fear of upsetting them. This need to protect family members served to isolate them from a possible source of support. This concurs with findings on `conversational isolationism' by Woods and Earp (1978). It is futher postulated that a possible reason for not confiding in family members is the desire to minimise the feeling of being `different'.

5.4.3 Losses

Table VIII LOSSES

	Members											
Losses	**1**	**2**	**3**	**4**	**5**	**6**	**7**	8	9	10	11	12
HEARING	-	*	-	-	-	-	*	-	-	-	-	-
MEMORY	-	*	*	-	-	*	*	*	*	-	*	-
CONCENTRATION	-	*	-	-	-	-	*	*	-	*	-	-
EYE PROBLEMS	-	*	-	-	-	*	-	-	*	-	-	-
PERIPHIRAL	-	*	*	-	*	*	*	*	*	*	-	*
ENERGY	*	*	*	*	*	*	*	*	-	*	-	*
SEXUAL FUNCTION	-	-	-	-	-	-	*	-	-	*	-	*
FERTILITY	-	*	-	*	-	-	-	-	-	-	-	-
RELATIONSHIPS	*	*	*	*	*	*	-	-	-	-	-	*
SELF-CONFIDENCE	-	*	*	-	-	-	-	-	-	-	-	*
SELF-IMAGE	*	*	-	*	*	-	-	-	-	-	-	*
SELF-ESTEEM	-	*	-	*	-	*	-	-	-	-	-	*
INDEPENDENCE	-	*	*	*	*	-	-	-	-	-	-	*

* indicates positive response
\- indicates no acknowledgement/absent during discussion

A loss refers to a partial or complete loss of a previous level of functioning or sensation, and may be temporary or permanent. A loss can be either physical, which pertains to a loss of functioning in certain areas for example, loss of memory; or emotional losses such as a loss of relationships, loss of confidence and independence. There is an interplay between emotional and physical losses as physical losses often lead to emotional losses. Loss was a strong recurrent theme affecting all of the members in one way or another (refer to Table V).

5.4.3.1 Loss of Energy

A problem experienced by most of the members was loss of energy (refer to Table VIII). Sometimes the loss of energy reached endemic proportions. This is illustrated in member 1's statement that she experienced a `profound lethargy which was overwhelming'. Coping with fatigue usually took the form of rest and sleep. This is clearly illustrated by member 2:

> `I feel that my body needed sleep...for two months after the transplant I would wake up in the mornings, get dressed, eat breakfast and return to bed where I would "pass out" until lunch time. I would get up for lunch and once again sleep for the entire afternoon. Seven years later I still require my rest in the afternoons.'

Sharing of the experience of fatigue resulted in a common understanding that loss of energy was a normal part of the BMT process. This resulted in normalisation of the experience and the expectation that it would eventually resolve itself.

Discussion: Loss of energy continued to be a problem for most of the members, although it was experienced to a lesser degree by the members who were out of the BMT for more than a year. Fobair et al. (cited in Welch-McCaffrey et al. 1989) found that survivors under 34 years experienced a return of energy within one year. In the current study, six of the ten survivors were in the first year post BMT. Hence, it is too early to make any extrapolations regarding Fobair et al.'s findings. Generally, survivors in this study have been experiencing slow increases in energy levels. With the exception of one member, those members who were out of BMT for more than one year, did seem to be satisfied with their energy levels. The interrelationship of physical and psychosocial sequelae was clearly illustrated in one of the members over 40 years of age who experienced energy loss and clinical depression, which is in keeping with the findings of a study by Fobair et al. (cited in Welch-McCaffrey et al. 1989). Members with low energy levels were encouraged by

the improvement of energy levels in fellow survivors, in that they were able to anticipate a likewise improvement in themselves.

5.4.3.2 Loss of memory

With one exception, loss of memory did not refer to amnesia, but rather to difficulty in remembering, absent mindedness or forgetfulness. Half of the group members complained of memory loss (refer to Table VIII). Most of the members thought that this problem was something that affected them exclusively as is evident from member 3's comment:

> `I thought that as I had been at home for a year I was out of practice. I put it down to the fact that I was lazy and not trying hard enough. I did not realise that this was something that other people experienced as well.'

All of the members who experienced this problem agreed that there was a definite deterioration in their memory function since the BMT. Member 6 was quite candid in saying:

> `My memory is definitely worse than it was. I had so much treatment to my brain, and I am positive that this is as a result of that. I know what I was capable of before. I have to compensate by writing things down...as the Chinese proverb goes..."faded ink is more reliable than a tentative memory!'"

Conversely, member 11 justified the deterioration in his memory as is evident in the following comment:

> `I notice that my short term memory is worse, and I have to write things down to remind myself. I would go `nuts' if I let it worry me, so I just put it down to old age.'

For member 2, memory loss negatively influenced her ability to perform her occupational tasks and increased her stress levels. Member 2 recognised the problem and was able to confront it as is indicated by the following statement:

> `Someone didn't want to deal with me at work because I was too absent minded. I was really shocked and upset as I tried so hard. It dented my self-esteem, but I realised that I had to get some feedback so that I could try and improve myself.'

The majority of patients experienced a sense of relief at hearing that this was a known side effect. However, member 8 commented that he found it disconcerting to discover that he was not merely out of practice, but that this was a problem that may not be resolved.

Discussion: Memory was a problem for seven of the group members. There is no conclusive evidence in the literature as to the cause (Adrykowski 1994). However, anecdotal evidence in this study would suggest that investigation of pre-treatment and pre and post BMT levels of cognitive functioning is warranted. The members acknowleged that they had not discussed their memory loss with their physicians, as they had been unaware that it was a possible side effect. They had rationalised their deficits with the result that it was not documented. This led to the Department of Haematology's inability to recognise this as a problem experienced by survivors, in this particular case. This new awareness is important insofar as prospective BMT patients need information and counselling in terms of the possiblity of this side effect occuring. With the exception of one member, all of these members also experience difficulty with anxiety. It is possible that anxiety and\or depression could be a contributary factor to loss of memory function and visa versa.

5.4.3.3 Loss of sexual functioning

A topic that was raised in two of the sessions was that of loss of sexual functioning. No female members acknowledged this as a problem. Half of the male patients admitted to experiencing difficulties with sexual function (refer to Table VIII). Member 12 stated that:

> `Nothing sexual has functioned. I have no desire and at times I think I am a eunuch. I don't feel masculine since my discharge from the hospital.'

Members differed in their approach to dealing with this problem. The married members appeared to cope better, in part due to their wives' support, as is illustrated in member 10's comment:

> `Talking about this with my wife has made it easier. She has experienced my difficulties and is very understanding. I feel confident that my function will return. It is just a matter of time.'

Conversely, member 12 found that it pervaded all aspects of his life as is clearly illustrated in the following statement:

> `I try and distract my thoughts by reading and going on long walks, but I can't stop thinking about it. I find I am avoiding social contact with women, as I am afraid of getting into an emotional relationship for fear of the next step.'

The benefits of both catharsis and group support are cogently expressed in member 12's comment:

> `It is such a relief to be able to talk about this, I feel as though a 3 ton person has just climbed off my shoulders...I have felt like a tank commander who has been besieged for the last year, and at last the troops have arrived!'

Discussion: During the discussion of loss of sexual functioning only three of the six men in the group were present. All of those present had been out of BMT for less than a year. Two of them acknowledged that this was a current problem, whilst the other member admitted that the problem had been resolved. One of those members for whom it was a current problem, was single with very little social support and a recently terminated intimate relationship. He admitted to feeling very traumatised by this experience, which undermined his self-esteem and self confidence. Lack of sexual functioning appeared to be more of a problem for him than the other two

married members. This would support the finding by Schmale et al.(1983) who noted that cancer survivors without significant relationships, were more psychologically distressed than their counterparts who had support. One woman admitted that she experienced no sexual difficulties post BMT. Of the four women present, all appeared to be uncomfortable to discuss this issue and did not seem to want to engage in this discussion from their own perspectives. It is recognised that this may not be a problem for members, or that members were not sexually active and were therefore unable to identify this as a problem. However, it is also possible that the topic was too threatening to discuss in an open group. Loss of sexual functioning may therefore be more of a problem than survivors may be willing to admit.

5.4.3.4 Loss of fertility

This topic was only raised on one occasion but was discussed at some length by the members. Loss of fertility was discussed mainly in terms of the women in the group. Four women were present in the group. Two members acknowledged that this is\has been a concern for them, whilst one woman chose not to become involved in the discussion. The fourth woman, a grandmother, had no intention of having more children. Of the four women present during this group session, two were single with no children and two were married, one with adult children and the other with one young child. Member 4, the young mother, was the only member who acknowledged that the loss of fertility was a source of great anguish for her. This is substantiated by the following excerpt which was expressed with a myriad of emotions.

> `I feel that I should be satisfied with my one child, and I do love him dearly, but I know that both he and his father would've liked another baby...I feel like such a failure. Whenever I go to the mall all I seem to see are pregnant women, and I want to kick them!...My body has let me down and I feel so bad...everyone else seems to be having a baby and I'm stuck...I accept that I've had leukaemia, but it just came at the wrong time. I wish it could've happened after my second baby.'

Member 2 acknowledged that there were times when she thought about the fact that she might be unable to bear children, but this did not seem to be a current concern for her. She added:

> `I'm not sure that it is impossible...but if it is, I would adopt. My fiancè has two children from a previous marriage, so I will have two children.'

Two of the members felt that they would like to undergo tests to confirm their inability to fall pregnant. Member 4 thought that she would be able to accept it better once she reached the age that she would have ordinarily been unable to conceive. One of the members shared that she had not been aware of the need for hormone replacements. When she noticed a sudden deterioration in terms of aging, she had been very distressed.

Discussion: Loss of fertility was discussed mainly in terms of the women in the group. This may have been due to the fact that those men who were present in the group had completed their families and fertility was no longer an issue for them. This would seem in part to support the findings by Welch-McCaffrey (1989) that a major stressor for unmarried survivors is that of sterility. In the researcher's opinion however, marital status does not appear to be the only factor that influences a survivors acceptance of sterility. Developmental stage, circumstances and previous hopes and expectations in terms of the size of a family also play a role. With the exception of one female member, for whom it was a major problem, denial and rationalisation appeared to be used as a coping mechanisms. It is acknowledged however, that the issue of loss of fertility may have been worked through for some members. With the exception of one member who expressed feelings of sadness, loss of control, guilt and anger, members chose to approach the subject in terms of possible solutions rather than focusing on the painful feelings of loss and mourning.

5.4.3.5 Loss of relationships

This was a theme that arose on a regular basis with most of the members participating. More than half of the members experienced losses in terms of relationships (refer to Table VIII). Three people felt that their diagnosis of cancer directly contributed to the breakdown of their intimate relationships with two of these members suffering traumatic losses in terms of broken engagements as is highlighted by member 3's statement:

> `The fact that my fiancè never understood was more distressing than the fact that I got cancer. Our relationship didn't go well from the time that I was diagnosed, I finally ended it just before the transplant.'

Loss of friendship was a problem for four members. At times this was due to the member's need to relocate so as to receive treatment. This is clearly illustrated by member 4's recollections:

> `We had to move to Cape Town so that I could receive treatment and undergo the BMT. The adjustment to a new home and a new community was difficult as I had no friends.'

All of these members found that it was difficult to come to terms with the loss of relationships stemming from the fact that they had cancer and an example of this is the comment by member 3.

> `It was easier to block out my feelings. I'm starting to deal with it in little bits and pieces now and I'm slowly starting to feel again.'

Discussion: Survivors experienced a need for friendships and peer support during their time of crises and BMT. Ferrell et al (1992) found a similar need expressed by subjects in their study. Loss of relationships occured early on in the treatment phase of their cancer and members were dealing with this unresolved pain in the group. It is possible that members may have unconsciously anticipated a rejection in their intimate relationships and may have thus partly facilitated the termination of

that relationship as a self-protective mechanism. Whatever the dynamic, the act of terminating a relationship or of being actively rejected was clearly very painful and was seen as a betrayal, which often resulted in loss of trust. This directly affected members' ability to engage in new relationships. Concern was expressed by the members about the timing of disclosing their previous diagnosis of cancer during courtship. Fear of rejection and\or making a fool of themselves inhibited their willingness to risk new relationships. Members hesitation about embarking on intimate relationships concurs with the research by Cella and Tross (1986) who established that survivors were less inclined towards intimacy.

The loss of friendships was also very traumatic for members. The pain of being abandoned by friends was so great that when the friends attempted to make amends, they were often either punished or disregarded by the survivors.

5.4.3.6 Loss of self image

The issue of loss of self image came up intermittently and was dealt with in passing by the majority of members. Most of the comments gave the impression of people rejoicing in their return to normality in terms of their appearance as opposed to focusing on the loss. An example of this was the comment of having achieved the notable milestone of needing to have a haircut. Three of the members referred to loss of self image as a current issue which caused them some distress. One of the members felt less of a man since his transplant, whilst one member felt humiliated by the fact that she experienced panic attacks - she was concerned as to how she appeared during one of these attacks. Member 2 described her experience as follows:

> `At least you look normal! For years I looked so ill and I looked so different to how I looked before. If anyone looked at me I thought it was because I didn't have hair. I could never believe that anyone would look at me and find me attractive. People that I grew up with didn't recognise me, and when they realised who I was, they cringed. It has been a very slow and painful process.'

Discussion: Those members who acknowledged that loss of self image was a current concern admitted that it had an impact on both how they and others viewed them, which in turn negatively influenced their self-esteem. Furthermore, it negatively impacted on their ability to socialise and form relationships. Improvements in terms of external appearances and physical recovery were also indicators of a move towards internal wellbeing. Unlike other members who rejoiced in their improvement some members regarded their appearance as reminders of their illness which supports the suggestion of Wingard et al. (1992) that physical changes such as decreased stamina, hair loss and skin changes from GVHD can affect self image negatively.

5.4.4 Self-concept

Issues relating to self-concept was a recurrent theme which was discussed in the majority of sessions. Self-concept refers to the members' evaluation and\or insights of themselves. Positive self-concept refers to members taking cognisance of their more positive attributes and\or recognising and accepting themselves in spite of their apparent\perceived shortcomings. Conversely, negative self-concept refers to members being self-critical and judgemental of their apparent\perceived shortcomings.

Table IX SELF-CONCEPT

	Members											
Self-Concept	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
POSITIVE	*	*	*	*	-	-	*	*	-	-	-	*
NEGATIVE	-	*	*	*	-	*	*	-	-	-	-	*

* indicates positive response
- indicates no acknowledgement/absent during discussion

5.4.4.1 Positive self-concept

Over half of the cohort acknowledged growth in one form or another as a result of this experience (refer to Table IX). This is clearly illustrated by member 7's comment that:

> `If this procedure has not meant anything to you so that you change things for the better, then I don't know what would. My attitude and priorities have changed. The gentler side of my personality has come to the fore.'

Member 3 concured that her priorities had also changed and that she was able to `let go of little things more easily'. Four members felt that they were more sensitive within themselves. This was not viewed as a negative aspect of themselves, but rather as a reality. This was highlighted by member 4's comment that `I'm not as able to cope with things as I was in the past. I'm much more sensitive.' Three members felt that they were more empathic towards others while three felt that they were more patient. Some members admitted that their personal relationships had also benefited due to their experiences, as they felt emotionally closer to their spouse or parents.

Discussion: Studies by Welch-McCaffrey et al.(1989) and Andrykowski et al.(1993) indicated that an event with significant negative implications can result in positive psychosocial change. Similarly, in this study, group members also experienced positive psychosocial change in spite of the traumatic experience of having undergone a BMT.

5.4.4.2 Negative self-concept

Half of the members were self critical or judgemental about their perceived shortcomings (refer to Table IX). Members acknowledged that the adjustment post BMT was difficult, nevertheless they frequently admonished themselves for not being `good enough' or for not coping well enough. This is substantiated by a number of comments made by the members, for example: member 12 called himself a `chicken' for not being willing to take risks in initiating relationships since his diagnosis of impotence, while member 6 expressed annoyance at herself for not coping with her panic attacks and member 3 blamed herself for being lazy when she could not remember things.

Member 7 criticised himself for not being a better person since the BMT. This is clearly demonstrated in the following annotation:

> `I am concerned that certain bad personality traits are re-emerging. I thought that after all I had been through, I would be a better person. When I was in hospital I had a lot of time to think about how I would change when I came out. Not major changes, but changes in general attitude for example. Now I find that it is difficult to accept myself, and not put myself down when I feel that I am falling short of the promises that I made myself in hospital.'

This theme was strongly interwoven with the theme of guilt of their own shortcomings and of failed promises to God.

Discussion: Some cancer patients may initially regard their diagnosis as a punishment for something they may or may not have done. However, it is interesting to note that post BMT survivors in this study conceptualise things rather differently. They seem to have moved beyond self-blame as a cause for their cancer and are more critical in terms of their falling short of their own expectations during their post BMT adjustment phase. This would seem to support the work of Mullan (1985) who describes different psychological reactions to the three periods\phases of survival.

5.4.5 Fear

Fear was mainly mentioned in terms of fear of infection and subsequent admission and the fear of relapse. Most of the members were involved in these discussions. Fear of death was referred to obliquely.

Table X FEAR

	Members											
Fear	1	2	3	4	5	6	7	8	9	10	11	12
INFECT/ADMISS	-	-	-	-	*	*	*	-	-	-	-	-
RELAPSE	-	*	-	*	-	-	*	*	-	-	-	*
DEATH	-	-	-	-	-	-	*	-	-	-	-	-

* indicates positive response
\- indicates no acknowledgement/absent during discussion

5.4.5.1 Fear of infection and admission

The three members who were concerned about this were all members who had undergone BMT recently (refer to Table X). Member 7 made the following comment:

> 'I find it difficult to go back. It sets me back psychologically. It reminds me of the first experience which was so traumatic. I feel that it is opening up the wound again.'

Coping took two forms: firstly, by making sure they looked after themselves by avoiding situations that incurred risk, as is clearly illustrated by member 12 statement: "You should try and avoid situations that are dangerous for you, it's wise not to take a chance."

Secondly, by supplementing their diets with vitamins as was the case with two of the members, and\or continuing to take some of their medication, as a form of insurance although the doctors had told them that they were no longer necessary. Reasons for this were given as fear of infections and subsequent admission as is clearly indicated by member 6's comment:

> `I was told I could stop taking my pills, but I continue to take them as I find them helpful and I am afraid of getting an infection.'

Discussion: The group found it difficult to acknowledge that the fear of infection or admission was part of the same fear of relapse. Rather it was viewed as preventing the repetition of the traumatic experience of being in the protective isolation unit. However, it is likely that the unconscious fear is that of a relapse.

5.4.5.2 Fear of relapse

Most members appeared to carry on with their lives, apparently not giving the possibility of relapse much thought, until they became ill as is illustrated by member 4's comment:

> `I'm so busy with day to day living, and enjoying every day as it comes that I don't think about it. It's only when I get a cold\flu that won't go away that I think about the possiblity of relapse. I get scared, so I try not to think about it.'

Members appeared to be divided in their opinions of how to cope with

thoughts of relapse. This is clearly highlighted by member 2's opinion that:

> `It is not healthy to think in terms of the possiblity of relapsing, and I don't allow myself to think like that. I don't even keep it in awareness. I never think `what if'. The whole experience was so heavy for me. I thank God for my health and think that I am healed.'

This was supported by member 7 who felt that `by thinking about it one digs up the negative'. Conversely, member 12 was concerned that stress could cause a relapse. This is evident from his comment:

> `If you don't resolve external stress factors, you stand a better chance of relapse. If you don't want to be vulnerable you must do your bit and sort out your problems. If you leave your problems to fester, this bloody thing will be back again. You can never put it behind you, you can never relax...it is always lurking and waiting.'

Four of the members acknowledged the need to keep busy so that they didn't have the time or energy to think about the scary possibilities of relapse.

Discussion: The concern of relapse versus cure referred to by Tross and Holland (1990) and the Damocles Syndrome mentioned by Koocher and O'Malley (1981) was seldom directly addressed in the group. However, it appeared to be a deeply ingrained and underlying fear for most of the members. There was some initial resistance to this topic which finally emerged in group session 11. The discussion surrounding the fear of relapse was closely connected with a debate amongst the members of whether or not one could refer to their state as one of "cure" or one of "remission." On the one hand, there seemed to be a concern that thinking about the possiblity of relapse, or holding it in awareness, would increase the likelihood of that event occurring, whilst on the other hand, it was felt that to think about the possiblity of relapse was not a case of bringing up the negative, but rather that if the thought of remission was held in mind, and the survivor actively pursued a healthy lifestyle, it would not be tempting fate. The role of the individual in

maintaining a remission state, and the extent to which self-blame could be apportioned in the event of a relapse occurring, was interwoven in this discussion. Survivors were therefore able to choose a way of adapting, which they felt was most likely to increase their chances of survival. This supports Rowland's view (1990b) that the patient's ability to adapt is something over which he\she has control.

The group questioned the cause of a diagnosis of cancer and reasons for relapsing. It was interesting to note that discussion around the possiblity of cancer being caused by industrial pollution or poor diet for example, seemed to be acceptable and received attention from the members. However, when the question "why?" was asked, it was quickly rejected by some of the members as being a question with no answer and consequently did not warrant discussion. This is in contrast to the suggestion by Curbo et al.(1993) that the process of searching for meaning itself, even if the answers cannot be found, may be of great significance in the healing process.

5.4.5.3 Fear of death

With the exception of one member who admitted being afraid of dying, this fear was referred to obliquely (refer to Table X). Members did not deny a fear of death but chose to avoid the topic if mentioned by the facilitators during interpretations or clarification. Yet, it appeared to be an underlying concern.

Discussion: A reason posited for the member's resistance to discuss death in the group may be that they have had to face the prospect of their own mortality on a daily basis. The group was regarded as a positive experience and the discussion of death was therefore avoided.

5.4.6 Guilt

Table XI GUILT

Members

	1	2	3	4	5	6	7	8	9	10	11	12
GUILT	-	*	*	*	-	-	*	-	-	-	-	*

* indicates positive response
- indicates no acknowledgement/absent during discussion

Guilt was a recurrent and strong theme that received a lot of attention for all that it was an issue for less than half of the members (refer to Table XI). Guilt took various forms including guilt for not being able to bear a child and guilt for being a burden, as is highlighted by member 2's disclosure:

> `I feel guilty that my 67 year old widowed mother still has to work to support us both, she finds it very difficult and exhausting and sometimes I don't even have the energy to help her with things.'

A predominant focus within this theme of guilt were the strong feelings of member 7 who felt that he should be doing something more worthwhile and that he was not appreciating life enough. Failed promises resulted in much guilt, as is evident by his statement:

> `I feel that I have been given a second chance by God and I feel guilty that I seem to be back to my old ways. Some days I feel wonderful and life is great, and other days I feel as though I need a kick up the pants because I don't appreciate that I survived. I feel that I should be doing something more worthwhile with my life, I need to give something back.'

Only one other member recollected feeling guilty for failed promises. A few of the members echoed the feeling of having a second chance and appreciating life. The

need to `put something back' was another common finding. Some members were concerned about re-visiting the unit, for fear of re-evoking emotions that surrounded the traumatic experience. Another concern surrounded their ability to impart the `right information' which would encourage patients as opposed to alarming them.

Discussion: Survivors frequently experienced ambivalent feelings. Feelings of a second chance\re-birth, referred to as the Lazarus syndrome by Hackett (cited in Lesko 1990b), as well as feelings of guilt were expressed. The latter were bound up with feelings of failure as opposed to survivor guilt. Members felt guilty for issues that were both within their control and beyond their control. It is postulated that the ability to find a purpose or meaning in the course of events would facilitate coping as suggested by Moos and Tsu (1977), which in turn would lead to an increased sense of well being and a possible reduction of guilt. It is further postulated that feelings of depression and lack of motivation may have exacerbated survivors' feelings of guilt.

The need to `put something back' was discussed periodically throughout the fifteen sessions, but was more evident during the early stages of the group. It is possible that members initiated it at this point as a way of avoiding looking at their own needs. Without undermining the real and altruistic need to put something back, which in itself is very empowering for the survivors, there may also be an element of the need to re-work the traumatic experience from a vantage point that is one step removed.

5.4.7 Social

The areas of social interaction and social withdrawal are discussed under this theme. It was raised in less than half of the groups, but was discussed at length by most of the members (refer to Table V).

Table XII SOCIAL

Members

Social	1	2	3	4	5	6	7	8	9	10	11	12
INTERACTION	*	*	*	*	-	*	*	*	-	-	-	*
WITHDRAWAL	*	*	*	*	-	*	*	*	-	-	-	*

* indicates positive response
- indicates no acknowledgement/absent during discussion

5.4.7.1 Social interaction

The majority of members experienced difficulty with social interaction (refer to Table XII). Member 2 expressed her difficulties in the following manner:

> `In the beginning I found it very very hard. I felt very isolated. I couldn't relate to anything anyone spoke about. I wasn't part of their world and they weren't part of mine. Just the fact that I was not working, or able to play sport and socialise easily affected a large area of the conversation. I felt inadequate and didn't think that I had much to give. I couldn't chatter or talk lightheartedly.'

Member 8 echoed this experience:

> `I find it an effort to think about what people are saying and then have to respond to their conversation so I tend to sit there and smile. I find that I avoid groups of people and feel much more comfortable on a one to one basis.'

Some of the members conceded that finding something to talk about, other than BMT was difficult. Member 4 voiced the opinion that she had an important need to talk about her BMT, she did however, recognise that the topic was not of interest to everyone she met in social situations, so she viewed it as a challenge to try and not talk about the BMT all the time. In the event that she did speak about it and people

did not respond to her in the manner in which she desired, she rebuffed them, justifying that `they weren't worth it anyway'.

Most of the members found that they coped better with one-to-one interaction, as opposed to interaction with groups of people. One member relied on family to ease the difficulties of socialising.

Discussion: The majority of members in the group experienced difficulties with social interaction post BMT. It appeared that survivors experienced personal inadequacy and heightened vulnerablilty in social situations which would concur with the findings by Cella and Tross (1986) that mild psychological concerns in survivors may be evident. The findings in this study concur with the observations by Koocher and O'Malley (1981) that cancer survivors, although capable of functioning effectively in social-interpersonal roles, experience subtle differences in self-concept, motivation and sense of being-in-the-world.

5.4.7.2 Social withdrawal

Social withdrawal was experienced by the majority of members (refer to Table XII). The following reasons were cited for withdrawing: Firstly, difficulties with mood and memory, as is illustrated by member 7 who admitted avoiding social contact because he was unable to remember peoples' names, nor was he in the mood to socialise. Secondly, feeling uncomfortable in social situations. Thirdly, a loss of trust in relationships and the fear of being hurt again. The latter was the experience of four members and is clearly illustrated by member 1's admission:

> `I was very hurt by my friends deserting me. I refused to be friendly with them when they made overtures of friendship towards me. I didn't feel that I could put myself in the position of being hurt again.'

Discussion: Withdrawing from social situations appeared to be a coping response. The need to protect themselves from being emotionally vulnerable appeared to be a motivating factor in many instances. This concurs with Welch-McCaffrey et al. (1989) who suggested that self isolation is indicitive of an interpersonal source of conflict. This could be due in part to the stress experienced in forming new relationships and having to guage the degree of disclosure in terms of their past history of cancer. In this study however, survivors appeared to avoid social interaction regardless of whether it was a new or familiar situation for them which would seem to support the assertion by Cella and Tross (1986) that a history of cancer may increase the survivor's sense of social isolation.

5.4.8 Religion

Table XIII RELIGION

Members

	1	2	3	4	5	6	7	8	9	10	11	12
RELIGION	-	*	*	*	-	-	*	-	*	-	-	*

* indicates positive response
\- indicates no acknowledgement/absent during discussion

Some of the members had renewed and strengthened their relationship with God, while others had not. It was nevertheless acknowledged that the process of having and surviving cancer was still traumatic, despite a relationship with God. Furthermore, members may have periodically experienced difficulties in their relationship with God. Some members acknowledged experiencing periods of alienation from God during their illness, which they found very distressing. Members 2 and 3 felt that they were able to hand their problems over to God so that

He would have control. Religion was acknowledged to be an enormous support to some members who felt that God had given them the ability to cope and was the reason for their survival. Guilt was expressed by a member who had not strengthened these bonds with God. Member 8 however, had a different outlook as illustrated below:

> `I find it fantastic how God helps so many people through this and gives them more than themselves to rely on. When they are going downhill there is somone\something to sustain them. However, I have been disillusioned, and I believe that you must believe in yourself and rely on yourself and it must be internalised ... you must be the master of your own universe.'

Discussion: The group discussions around religion did not revolve around questioning God, which in the researcher's experience is often the case in newly diagnosed patients. Instead, the group focused on the enormous benefits of having faith and the difficulties of maintaining faith under trying circumstances. One member appeared to defend against being disillusioned with religion by utilising rationalisation, while another member acknowleged anxiety and guilt in terms of his perceived lack of relationship with God. This supports the suggestion by Blazer et al. (cited in Rowland 1990:47) that higher levels of self reported well being is associated with religious convictions and beliefs.

5.4.9 General

In general, members acknowledged that the adaption post transplant was difficult. However, they expressed the view that they were fortunate in having a second chance and most members expressed a renewed and greater appreciation for life. For some members, the family unit had been strengthened and the way in which life was viewed had been altered for the better. Members agreed that the experience forever leaves an impression on the survivor. This was succinctly voiced by member 2 who said that:

> `Some people comment that "it is all over now", but it isn't really. In a way you forget, but part of it remains with you always.'

In relation to the experience of numerous losses, member 2 made this profound statement:

> `It depends on from which aspect you look at it. I would rather have survived this than not, so you have to do with what you have got. I definitely wasn't ready to go to heaven, although I believe that it is a wonderful place.'

An interesting observation was that members shared with one another that they would feel considerably better after the third month post BMT and newer members confirmed this.

Members enjoyed the fellowship of the group, a sharing amongst people who truly understood what their journey had entailed and who knew many of the challenges that awaited them.

Discussion: The enormous impact that the BMT experience had on the members was evident. In terms of the group experience, it was striking to observe that most of the members found common ground through shared experiences. This facilitated the ease with which the open group assimilated new members. Members were able to relate to one another with a deep sense of empathy and understanding and felt comfort in the knowledge that they were not alone in their experiences.

One member remarked that the circle of the group symbolised safety and wholeness. This seemed to be the experience of most of the group members. The group provided a space for some of the members to express fears and concerns that they had not been able to share with anyone else thereby offering peer support and reducing feelings of isolation for some members. As stated in section 5.4.2.3, this supports the findings of Woods and Earp (1978). Members endured losses and

obtained gains as stated in section 5.4.4.1. This concurs with findings by Andrykowski et al. (1993) and Welch-McCaffrey et al. (1989).

The journey from diagnosis to extended\permanent survival is dynamic and ongoing with members needing to adapt to different issues in each phase. The concept of `seasons of survival' as introduced by Mullan's (1985) was highly applicable to this group. Accordingly members of the group were either in the `extended survival' or `permanent survival' phase, and to a large extent this influenced which issues were brought up in the group. Members agreed that the experience of having survived cancer left an emotional impression on them and remained an intergral part of them, regardless of the fact that they were in the `extended or permanent survival phases'. This is similar to the experience described by Mullan (1985).

An interesting finding was that members in this study appeared to feel better after the third month. This is in contrast with the results of a study by Syrjala et al. (1993) who noticed that functioning of BMT survivors was most impaired 90 days post BMT. A possible explanation for this is that in the current study, the members' expectations may somehow have influenced their perceptions of their progress. Long-standing members expressed amazement and were united in their belief that the new members would follow their own experience and feel better by the third month. This introduced the expectation of an increased sense of wellbeing within a certain time period. It appeared that a `curse' had been magically lifted and life had consequently improved.

Group members utilised numerous coping strategies in terms of coping with the diagnosis and survival of cancer. It appeared that individual adjustment was influenced by the survivor's premorbid personality and coping style, their access to support and the duration and experience of the treatment. The range of coping techniques utilised by the group included denial, avoidance and confrontation. In

terms of utilising the group, members were able to give and receive support, employ problem solving techniques and seek relevant information from fellow members and\or facilitators.

5.4.10 Results and discussion of the evaluation form

The results of the evaluation form (refer to Appendix B) was not the main thrust of the research. However, feedback from the members as to the value of the group was considered important.

In terms of verbal feedback given in the group, members expressed their appreciation of being able to meet and feel supported by fellow survivors. One member was very encouraged by seeing the number of survivors increasing. Witnessing other members cope with adversity was also very encouraging for group members. One member felt more at peace with the whole experience as a result of attending the group, as he was able to realise that he was not alone in the journey towards rehabilitation. One member in particular experienced the group as being the single most important factor in recovery.

Members valued the opportunity to share experiences and listen to others, as well as help them with their difficulties where possible. There was a strong need for members to `put something back' which may have influenced the culture of advice-giving which did seem to prevail in the group. This was possibly an attempt to be of some assistance to fellow group members (which is appropriate in a support group), however, it may also have been an effort to try and remove the emotional pain experienced by both themselves and other members.

Members acknowledged that group was thought provoking for them, and that they often continued to think about the issues after the sessions. Furthermore, it offered them the opportunity to view their problems from a different perspective.

In terms of the evaluation form, (refer to Appendix C) the respondents appeared to be satisfied with the format and structure of the group sessions. Some members felt uncomfortable with the silences in the group and may have felt less threatened in a more structured group. One member particularly enjoyed the silences in the group as it was the first time that he had experienced silences as safe and secure. The possiblity of including family members in groups needs further exploration. Members appeared to be concerned about the lack of new membership in the group.

Sharing experiences and enjoying the fellowship in the group was highly valued by the members. Members liked the openness and the honesty within the group, which afforded them the opportunity of expressing their fears and concerns thereby experiencing relief as a result of the catharsis.

The factor that maintained the members continued commitment to the group was their desire to help other members as well as the opportunity to share their experiences. In terms of the benefits of the group, members were relieved to discover that they were not unique in their struggle and they felt understood by fellow members.

In general members appeared to be satisfied with the group and the facilitators, however, it should be recognised that they were aware that they were part of a study, which may have influenced their feedback.

CHAPTER SIX

CONCLUSION

6.1 MAIN CONCLUSIONS

Bone marrow transplantations at Groote Schuur Hospital offers a chance of a cure for many patients who have leukaemia, lymphoma, myeloma and aplastic anaemia. The process of BMT is long and difficult and makes many psychological and physical demands on the patients' and their families. In order to offer an appropriate service to survivors it was considered important to ascertain what psychosocial difficulties were experienced by survivors of this procedure. With this in mind, fifteen sessions of an ongoing support group were utilised to document and analyse the self-identified issues experienced by survivors.

This study was qualitative in nature and the researcher used first hand accounts of survivors which were largely anecdotal. The study used a small sample, therefore the findings cannot be extrapolated and generalised to the broader population. As a result of the language exclusion criteria, which was restricted to English and Afrikaans language groups, not all race groups were represented. Therefore, the study is not truly representative of all cancer patients in South Africa.

In general, the main findings of this study concurred with the findings in the literature. There is evidence that a general sense of vulnerability and anxiety persists among a significant proportion of the group members. The levels of depression were not significant, but as this study focused on self-identified issues, it is possible that depression was under reported. Furthermore, member's understanding and recognition of what constitutes depression, may vary.

An underlying anxiety that pervaded the group was the concern about the possibility of relapse. Although still present, this appeared to be less of a concern for some members who had been out of the transplantation programme for longer periods. Members in the group experienced numerous losses as a result of this experience. Most of the members experienced difficulties as a result of low energy levels. This did seem to improve for most of the members over the eight months that the group met. The finding that most of the members experienced difficulties with memory indicates the need for further investigation.

Intimate relationships were also affected by the cancer experience. The married members expressed an improvement in their relationships with their partners, while single members experienced strained and broken relationships as a result of the diagnosis of cancer. Single members admitted to being anxious about initiating new relationships. In terms of difficulties with sexual functioning, the married members appeared to cope better with these difficulties than the single unsupported member. Feelings about the loss of fertility were not significant but may well have been under reported.

Re-entry into social situations was stressful for the majority of members. Feeling different, loss of confidence, difficulties with mood, memory and energy levels all contributed to members feeling inclined to withdraw from social situations or limit their interaction to a one-to-one basis.

Re-entry into work situations did not receive much attention. When this topic was raised, it dealt primarily with difficulties experienced in terms of lack of motivation and energy. Initial lack of confidence was also a problem, but seemed to resolve itself within a short period of time.

Members felt strongly about the need to be in contact with fellow survivors prior to their own transplants. Survivors also expressed a need to `put something back'. As a consequence of these `felt needs' in the group, current patients now have the opportunity to meet survivors prior to their BMT.

The general consensus in the group was that information needed to be user friendly and easily accessible. Recognising the complexity of giving information, members nevertheless argued that open and honest communication enhanced trust between health professionals and themselves and increased their ability to cope.

An area that appeared to differ from the literature in this particular group, was the expectation of increased well-being by the third month. This seemed to positively influence the member's appraisal of their health status and functioning at three months.

Survivors also expressed areas of growth and secondary benefits in terms of having survived cancer. These included improved relationships, strengthening of the family unit, renewed interest in religion, increased self acceptance and the changing of attitudes and values.

It is important to obtain feedback and insights from patients themselves so that the service delivery is appropriate. As patients become better informed and more assertive, and medicine moves away from the paternalistic mode of functioning, it has a responsibility to be accountable and transparent to the consumer. Recognising the importance of the group to the members and the benefits they accrued through the group, is a helpful guide for further planning and intervention.

Surviving cancer marks the beginning of a new process. Although the psychological impact varies from patient to patient, the adaptation phase has it's own challenges

which must be confronted by survivors and their families. It is imperative that social workers are aware of these challenges that await survivors, in order to provide adequate preparation prior to discharge. Understanding that there are different phases in the survival framework, enables the social worker to anticipate the different issues being faced by the survivors during the different phases. This would facilitate a more appropriate service delivery which would be tailored to the survivor's needs. This could enhance the survivor's efforts at coping with the challenges of adaptation and possibly improve their quality of life. This approach would probably contain some of the anxiety experienced by the survivors who would feel more understood.

6.2 RECOMMENDATIONS

1. Information both prior to and post BMT needs to be more easily accessible and user friendly.

2. It would appear that survivors and their families need to be more adequately informed by the medical staff about possible side effects such as memory loss, infertility and sexual functioning. Furthermore, possible solutions or options that might minimise these problems, such as hormone replacement therapy, need to be explored with survivors. It is suggested that the social worker be responsible for heightening the awareness amongt the medical staff as to the psychological and social implications of these losses for patients and their failies. Sensitivity to patients needs, fears and fantasies about these losses should be highlighted. Referrals to the social worker should be routine so that patients and their families can start with the process of working through and coming to terms with these possible losses.

3. The BMT survivors should be utilised as a resource for patients awaiting BMT, thereby empowering the survivors and possibly meeting a need for BMT recipients. This process should be co-ordinated by the social worker on the unit.

4. Discharge meetings with patients and their families should be routinely held with medical and paramedical staff present. This meeting should cover the possible complications and further medical information and deal with anticipated physical and psychological reactions post discharge. Survivors and their families should be informed that reintegration and adjustment normally takes up to a year so that expectations for physical and psychological recovery are more realistic. Particular reference should be made in terms of the possible problem areas within relationships and social reintegration. Furthermore patients should be made aware of the resources that may facilitate their adaption process such as the support group, individual counselling and literature.

5. There has been an increasing emphasis on the need to demonstrate the cost-effectiveness of psychiatric and psychological intervention in medical settings (Forester et al. 1993). Social Workers are under pressure to provide services to an increasing number of people. It appears that a group was beneficial for survivors in that it offered them peer support and a space to explore their feelings, receive plus give support and exchange information. Group work may often be a more cost effective alternative to individual counselling. It is recognised that in certain instances individual counselling would be recommended. It is also possible that certain topics such as sexual functioning and infertility might be too threatening to discuss in a mixed gender group. Therefore, it would be valuable to offer a safe space for women and men to discuss these issues alone or in a single gender group. The opportunity for establishing groups for adolescent survivors as well as family members needs to be explored.

6. This study focused on a small section of the population. Further research needs to be conducted within different racial and cultural groups in order to be truly representative of South Africa's population.

7. A further recommendation is that research needs to be conducted in terms of memory loss. Another area that may warrant further investigation is the aspect of the self-fulfilling prophesy in terms of the members feeling better because they anticipate that they will.

In conclusion there is a general perception in society that individuals who are diagnosed with cancer are given a death sentence. It is important that health care professionals are the bearers of good news in terms of the enormous successes that treatments offer patients. The population of cancer survivors is ever increasing. It is appropriate therefore, that emphasis on survivor's biopsychosocial needs be assessed in order that an effective service be afforded to them. To this end, survivors should be attended to in rehabilitation clinics where the emphasis is on recuperation and reclaiming their lives. By witnessing the positive benefits of fellow survivors, hope is instilled in individuals for their own survival and well being.

APPENDIX A

Table XIV THE NEED TO GIVE AND RECEIVE SUPPORT & FOR GROUP FELLOWSHIP

Members

	1	2	3	4	5	6	7	8	9	10	11	12
GIVE SUPPORT	-	*	-	*	-	-	*	-	-	-	-	-
RECEIVE SUPPORT	*	*	-	*	-	*	-	-	-	-	-	*
FELLOWSHIP	-	*	-	*	-	*	*	*	*	-	-	*

* indicates positive response
\- indicates no acknowledgement/absent during discussion

Table XV ANGER AND FRUSTRATION

Members

	1	2	3	4	5	6	7	8	9	10	11	12
ANGER SELF	-	-	-	-	-	*	*	-	-	-	-	-
ANGER STAFF	-	-	*	-	-	*	-	-	-	-	-	*
ANGER OTHER	*	-	-	*	-	-	-	-	-	-	-	-
FRUSTRATION	-	*	-	*	-	*	*	-	-	-	-	*

* indicates positive response
\- indicates no acknowledgement/absent during discussion

Table XVI COPING

	Members											
Coping	1	2	3	4	5	6	7	8	9	10	11	12
EXPLORING OPTIONS	-	*	-	*	-	-	-	-	-	-	-	-
CONFRONTING	-	*	-	*	-	-	-	-	-	*	-	*
DENIAL\BLOCKING	-	*	*	-	-	-	-	-	-	-	*	*
DISTRACTION	-	*	*	*	*	-	*	-	-	-	-	*
KEEPING BUSY	-	*	*	*	-	-	*	-	-	-	-	-
AVOIDANCE	*	*	*	-	*	-	*	-	*	-	-	*
PERSEVERANCE	-	*	*	*	-	-	*	-	-	-	-	-
HUMOUR	-	-	-	-	-	-	-	*	-	-	-	*

* indicates positive response
\- indicates no acknowledgement/absent during discussion

APPENDIX B

EVALUATION OF THE POST BONE MARROW TRANSPLANTATION SUPPORT GROUP.

The evaluation has been designed in such a manner that it is very open-ended. I would appreciate it if you could take some time to think about your feelings about the group and answer **ALL** the questions in as much detail as possible.

If you do not have enough space for your answers please include extra sheets of paper but take care to number the relevant answers.

Name:.....
(You may remain anonymous if you wish. It should be borne in mind that anonymity will be respected in any event.)

1. Have you ever been involved with any other group besides this one?

2. What were your expectations of group? What did you hope to get out of the group?

3. Do you feel that the group met regularly enough?

4. How frequently would you like the meetings to be?

5. Was the length of each group meeting long enough, and if not, how long would you prefer to meet for?

6. Did the time of day of the group meetings suit you?

7. If not, what time would be more suitable?

8. Were you happy with the venue? If not where would you prefer to meet?

9. Were you happy with the format of the group? (e.g. would you have liked speakers, the group to be more structured etc.) If not, what were you unhappy about?

10. Were you happy with the structure of the group? (Size of group, gender ratio, race\culture\religion ratio, open format i.e. new members joining etc.) If not, what would you prefer?

11. What did you dislike about the group meetings?

12. What did you like about the group meetings?

13. What do you think were the factors of the group that maintained your continued commitment to the group?

14. What do you feel were the benefits of group for you?

15. Did the group live up to your expectations\ meet your needs or not? If not, howcome? If yes, in what way?

16. Thinking about the facilitators' in the group can you think of any ways in which they could improve their handling of the groups.

17. What did you particularly like about their handling of the groups?

18. Any other comments.

APPENDIX C

EVALUATION OF THE POST BONE MARROW TRANSPLANTATION SUPPORT GROUP.

QUESTION 1

Have you ever been involved with any other group besisdes this one ?	
YES	0
NO	7

QUESTION 9

Were you happy with the format of the group?(e.g. would you have liked speakers , the group to be more structured ect) If not, what were you unhappy about?	
HAPPY	6
WANTED TOPIC OF INTEREST	2
WANTED SPEAKERS	2

QUESTION10

Were you happy with the structure of the group? (Size of group, gender ratio, race\culture\religion ratio, open format i.e. new members joining etc.) If not, what would you prefer?	
MORE PATIENTS	1
NO PROBLEMS	5
INCLUDE FAMILY	1

QUESTION 11

What did you dislike about the group meetings?	
SILENCES	2
SOMETIMES LITTLE GAINED	1
NOTHING	4
ABSENTEEISM	1
TIME LIMIT	1

QUESTION 12

What did you like about the group meetings?	
SHARING EXPERIENCES	5
BEING UNDERSTOOD	1
HELPING OTHERS	2
VENTILATION/CATHARIS	3
EMPATHY	2
SECURITY IN SURVIVAL	1
FELLOWSHIP	5
OPENNESS/HONESTY	3
STIMULATING	1
CLOSENESS	1
SILENCES	1
COMMON EXPERIENCES	1
SAFETY	2
FEEDBACK	1

QUESTION 13

What do you think were the factors of the group that maintained your continued commitment to the group?	
WANTING TO HELP	4
FRIENDSHIP	1
RESPONSIBILITY TO OTHERS	1
SYMBIOTIC NEEDS	1
BEING REMINDED	1
SHARING	2
RESPONSIBLITY TO FACILITATOR	1
DESIRE TO GET BETTER	1
FRANKNESS	1
CONFIDENTIALITY	1
CLOSENESS	1
SILENCES	1
FACILITATORS THEMSELVES	1
COMMONALITY	1
SAFETY	1
FEEDBACK	1
CAMARADERIE	1
SUPPORT	1
UNDERSTANDING	1
PROBLEM SOLVING BENEFITS	1

QUESTION 14

What do you feel were the benefits of the group for you?	
NOT UNIQUE	2
NOT ALONE	1
COMING TO TERMS WITH ISSUES	1
SUPPORT	1
INFORMATION	1
EMPATHY	2
SURVIVAL STATS	1
SHARING & VENTILATION	2
BEING UNDERSTOOD	2
QUALITY OF LIFE INCREASED	1
SELF CONFIDENCE INCREASED	1
MOTIVATION INCREASED	1
ACCEPTANCE OF FATIGUE	1

QUESTION 15

Did the group live up to your expectations/ meet your needs or not? If not howcome? If yes, in what way?	
YES	6
NO	0
YES AND NO	1

QUESTION 16

Thinking about the facilitators' in the group can you think of any ways in which they could improve their handling of the groups?	
NO COMMENT	1
NO	5
ASSIST WITH INCREASING MEMBERSHIP	1

QUESTION 17

What did you particularly like about their handling of the groups?	
CONFIDENTIALITY RESPECTED	1
EMPATHETIC	1
ENCOURAGED SHARING	1
LISTENED/ INTERESTED	2
HELPFUL	1
ENABLING ATMOSPHERE	1
CO-ORDINATION BETWEEN FACILITATORS	2
RELAXED ATMOSPHERE	1

QUESTION 18

Any other comments?
I WILL MISS BEING IN THE GROUP
PERHAPS WE COULD HAVE A SUGGESTION BOX
COULD WE RECAP AT THE BEGINNING OF EACH MEETING?

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C. PERSONAL COMMUNICATION

NOVITZKY, N. Professor and Head of the Department of Haematology University of Cape Town and Groote Schuur Hospital, Cape Town

STEIN, M. Medical Officer, Department of Haematology Groote Schuur Hospital, Cape Town

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MEMORANDUM

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To: Jenith Shannon
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